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## **ABSTRACT**

### **U.S. AIR FORCE FAMILIES WITH YOUNG CHILDREN WHO HAVE SPECIAL NEEDS**

Carol Copeland

June 22, 2005

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This study surveyed Air Force families with young children who have special needs. A purposive sample from across the continental United States provided information regarding the types of needs experienced, the types of services desired, and the sources of services received. The 47 respondents provided information regarding the challenges they encountered in pursuing 112 services, the helpfulness of case managers and others, and their satisfaction with services. Additionally, they rated the perceived impact on the military career of having a child with special needs.

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YOUNG CHILDREN WHO HAVE SPECIAL NEEDS**

**by**

**Carol Copeland  
B.S., Virginia Polytechnic Institute & State University, 1983  
M.S.W., University of Houston, 1988**

**A Dissertation  
Submitted to the Faculty of the  
Graduate School of the University of Louisville  
in Partial Fulfillment of the Requirements  
for the Degree of**

**Doctor of Philosophy**

**Kent School of Social Work  
University of Louisville  
Louisville, Kentucky**

**and**

**College of Social Work  
University of Kentucky  
Lexington, Kentucky**

**August 2005**

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Carol Copeland

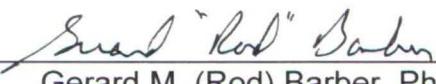
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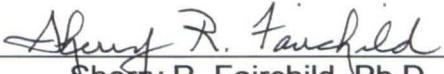
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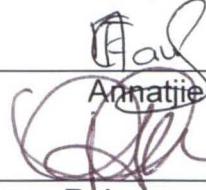
June 22, 2005

by the following Dissertation Committee:

  
Ruth Huber, Ph.D.

  
Gerard M. (Rod) Barber, Ph.D.

  
Sherry R. Fairchild, Ph.D.

  
Annatjie C. Faul, Ph.D.

  
Thomas R. Lawson, Ph.D., LTC (Ret.), USA

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and do not reflect the official policy or position of the United States Air Force,  
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## **CHAPTER I**

### **THE PURPOSE OF THIS RESEARCH**

Among human service professions, social work is perhaps the most concerned about the balance between society's adaptation to individuals and individuals' adaptation to society. A seminal and influential work for the vocation distinguished social work from professions in health, education, and religion, by emphasizing social work's focus on the totality of social and economic forces (vs. specific aspects of focus) that affect individuals, families and groups as they seek to adapt to their situations. Additionally, the authors asserted social work's integrating and instrumental functions in modifying communities to promote the social well being of citizens (Hollis & Taylor, 1951).

In order to strengthen the adaptive capacities of both individuals and social services, empirical evidence is needed to support effective program design and policy decisions (Rubin & Babbie, 2001). Those who serve the needs of potentially vulnerable populations have a responsibility to (a) consider the clients' perceptions and experiences, (b) consider the effect of policies and practices on beneficiaries, and (c) remain vigilant to unintentional consequences, especially to minority populations (Chambers, 2000; Freeman, 2000).

Social work devotes many of its resources to identifying and advocating for the needs of society's minorities, the most disadvantaged and therefore most

vulnerable members. The NASW Code of Ethics (1996) codifies social work's values regarding advocacy in section 6.01. One of these disadvantaged groups that receives social assistance is the disabled, and particularly disabled children. These children with special needs and their families are offered public assistance in order to meet a variety of social goals, including moral and pragmatic objectives.

To gain a better understanding of the issues inherent in families that include disabled individuals, this chapter includes sections on (a) moral and cost-saving objectives, (b) concern of the military regarding special needs, (c) a problem statement, (d) the focus of the study, and (e) research questions. This chapter then closes with a brief discussion of the study's methodological limitations.

### **Moral and Cost-saving Objectives**

Advocates for publicly supported services to children and their families, regardless of disability, cite moral principles evident in most religious tenets. Other considerations of a moral nature include the responsibility of society to socialize children into the behaviors that contribute to a democratic and moral society (Freeman, 2000; Karger & Stoesz, 2002; Loewenberg, Dolgoff & Harrington, 2000; Stevens & Wood, 1987).

In addition to these value-based perspectives, pragmatists cite the fiscal logic of preventive and early care alternatives. The adage *an ounce of prevention is worth a pound of cure* rings true, as services for many disabilities become more costly (in medical/ educational terms as well as in family hardship) as

children age. Warfield (1994) found that services initiated earlier resulted in greater improvements both for children and their interactions with their mothers, per \$1,000 spent by the state, and are likely therefore to be more cost effective. Oser and Cohen (2003) reported that "in the absence of early intervention, such developmental problems often get worse and can lead to secondary disabilities, which will be more expensive to address later" (p. 9). Effectiveness research indicates that services initiated earlier in a child's life, even if the focus is only on removing barriers to developmental trajectories, may be less costly to society (Blackman, 2002; Ysseldyke, Algozzine, & Thurlow, 1992).

Given that the American Academy of Pediatrics reports an estimated incidence of developmental or behavioral disorders in American children of 12 – 16% (American Academy of Pediatrics, 2001), the amount of money at stake is clearly substantial. Even using more conservative estimates of 2.2 – 10% (Hendrickson, Baldwin, & Allred, 2000) or of 3.6% (Bowe, 1995b), the lives of millions of people are impacted by services to children with special needs. These effects are both direct and indirect, as seen in the interests of employers, for whom the lost productivity of workers due to unmet family needs justifies their preventive and supportive investments in families. The military is one type of large employing organization that recognizes the value of identifying special needs families and providing the supports necessary for the service member to continue functional employment, particularly in a demanding and mobile lifestyle.

## **Concern of the Military with Regard to Special Needs**

This section will describe the current concern of the military with regard to children who have special needs in the following sections: (a) changing demographics in the military, (b) changing priorities of the military, an emphasis on families, (c) military family life, and (d) military social workers. The ability of military families to manage the care of one or more children with special health care or educational needs is ultimately a quality of life issue, and thus a significant retention concern for the military community. In an all-volunteer force, given the current world situation, military leaders are challenged to retain those in the service who face ongoing conflicts between work and family expectations. Geographically mobile military families with young children who are identified as having ongoing special needs, related to health care requirements or daily functioning abilities, may be viewed as a vulnerable population. Because of the non-standardized nature of American service delivery programs, with varying structures based on geographic locations, mobile families face additional hardships beyond those of other families with special needs children. The military has identified this concern and developed support programs, but as in all human service endeavors, the dynamic nature of families and of needed supports requires an ongoing evaluation of needs and service effectiveness.

### ***Changing Demographics in the Military***

Tremendous changes have occurred over the last four decades with regard to the importance of the family to military service retention. While the first federal role in health care and social welfare was seen in the military services as

early as the 1700s, it was solely focused at that time on protections and treatment of the individual soldier or sailor (Litman & Robins, 1984). Through World War II, most service members were single men; and if not, no special allowances were made for their families. This has certainly changed.

According to the 2001 Demographics Report of the Military Family Resource Center (MFRC, 2004), 51.4% of all active duty members are married and 44.1% have children. Women now comprise 14.9% of the active duty force, continuously increasing over the last 25 years. With the end of the draft, the voluntary nature of military service has necessitated a focus on what keeps people interested in continuing military service. To a large extent, the answer is *quality of life*.

### ***Changing Priorities of the Military: Emphasis on Families***

Quality of life is of keen interest to the leadership of the Department of Defense (DoD), according to the Military Family Research Institute (MFRI), as seen in the establishment of the Office of Military Community and Family Policy and related agencies within each branch of service. At the highest levels, the DoD is focused on three key work outcomes for military members: performance, retention, and satisfaction. The MFRI uses a domain-based approach in organizing its supporting research and 3 of the 6 major domains of life are directly related to aspects of early childhood services: community, parenting, and social support networks. The other research domains are employment, marriage, and self/well-being, which are certainly at least indirectly related (MFRI, 2004). These are the areas that have been identified as influencing performance in the

military, affecting retention rates in a volunteer military, and as factors in whether military families are satisfied with their lives. Programs that support these domains are considered key to the goals of the DoD.

Many of these programs are specific to military families with young children. According to the 2003 MFRC statistics (<http://www.mfrc-dodqol.org/stat.cfm>, downloaded Apr 20, 2005), the largest percentage of minor dependents of all active duty members is between birth and 5 years old (39.6%). This represents an increase from the 2001 report, which reported 38.5% of minor dependents were 5 years old or less. The total number of children represented (in the 2003 data) between ages 0 - 2 is 252,101 across all pay grades, and the total for ages 3 - 5 is 231,412. Specific to the Air Force, 123,806 of all minor dependents are younger than 6 years old. This figure represents 40% of the 309,142 Air Force dependents younger than 18 years old.

It is helpful to look at the rank of the service member as an indicator of parental age, experience and income, all of which are known to impact parenting (Halpern, 2000; Osofsky & Thompson, 2000). In the military, the lower ranks of both officer and enlisted personnel are typically under 26 years old and earning lower wages (some qualify for income assistance programs in many states). Among the lowest ranks of both officer and enlisted categories for all branches of service, there were 181,388 children under 6 years old in 2003, up from 177,451 children in 2001. While the exact number of service members connected with this group of children was not reported, it is known that 55.9% of all active duty members report family responsibilities and 58% of Air Force service members

report having a spouse, one or more children, and/or one or more adult dependents. Over half of all service members reported having their first child between ages 20 and 25, with 60% (6,210 persons) of all Air Force sponsors (members of the Air Force) reporting the birth of their first child when they were under 26 years old (MFRC, 2004)

While these numbers are small compared to the total number of parents and children in the U.S., the proportion of service members this represents to the military is a considerable group. To strain or lose that many service members due to unmet stressors involving the care of children would be devastating to mission accomplishment. Recognizing this, the military developed model programs for early childhood care and support that received presidential recognition (Clinton, 1997). A significant portion of the defense budget is dedicated to supporting military families in managing their specific concerns with aspects of military life, including the care of children. Not doing so is recognized as a significant threat to retention, performance and satisfaction of the volunteer force.

The increased awareness of the needs of families and of communities in supporting mobile service members has resulted in the development of numerous programs within the military environment. Specific sub-groups with special needs are identified in the military community for specific assistance. Within the Air Force (AF), these include the Exceptional Family Member Program (EFMP), the New Parent Support Program (NPSP), and the Special Needs Information and Assignment Coordination program (SNIAC), among others.

Other service branches, such as the U.S. Army and Navy, have similar programs. In these service-oriented programs, social workers and others work to balance the needs of the military as a whole (e.g., for a productive and committed work force) with the daily needs of individual children and families. Frequently this involves identifying which civilian or non-military supports are available, referring families, and identifying where existing services are not fully adequate for the needs of military families. These initiatives require ongoing study of military family life, of emerging service delivery systems, and effective advocacy. Just as the social service delivery system is dynamic, so are the emerging needs of military families.

### ***Military Family Life***

The nature of military life is that of change. Throughout a 20-year military career, it is not unusual for a family to move 10 times, involving several states and possibly foreign countries. According to Finkel, Kelley, and Ashby (2003), the DoD Selected Manpower Statistics of 1998 reported 1.2 million children lived in U.S. military families that year, with the typical military family moving every 2 to 3 years. For a mobile family with a special needs child, this frequency of geographic mobility represents ongoing challenges in negotiating access to state-based health care systems. In recognition of these challenges, the DoD has established services and procedures for the protection and assistance of special needs families. While each branch of service has its own names and regulatory guidance for these programs, assistance with relocation and service coordination is available for all service members. However, the DoD does not intend to

replicate civilian social institutions that serve military families well. With very few exceptions, the DoD has not been involved in the provision of education, leaving that to the discretion of the states. This has worked well because of society's acceptance of the obligation for, and benefits of, a free public education for children. Historical developments that emerged from the civil rights movement (e.g. Brown v. Board of Education, 1954) have resulted in a generally equitable, easily accessible system that is comparable across states.

Due to the historical evolution of medicine, though, the military has taken a more direct role in providing both direct care to families and the funding mechanisms for privatized care in order to reduce the fragmentation typical in the civilian sector (Kelly et al., 2002; Krauss et al., 2001). Unlike education, access to health care is obtained either by paying for it directly or through membership in a group for which a third party is willing to pay the costs associated with health care. Military families now receive a large part of their health care services through a contracted private insurance company, Tricare, which is managed regionally throughout the U.S. The DoD cannot be in the business of directly providing health, education, and specifically early intervention services to family members, and does not desire to duplicate existent services in the civilian community. Therefore, the focus of DoD-provided care is now in the provision of generalized primary care (including the early identification of special needs), and in providing information, referral, case management and indirect support services linked with the specializations possible within the civilian service structure.

Families with special needs children are served by a combination of military and civilian services, with reimbursement for allowed civilian medical services provided by Tricare. Currently there is no co-payment for authorized services required of military families and there are no personal funds expended by those receiving military provided services. However, much variation is seen in out-of-pocket costs for related services that are not currently provided by the military, or that are not seen as strictly medical in nature.

Given all of the above, it is fair to say that military families must continually navigate a complex system of services for children that involve both the public and private sectors, that intertwine state-based and federally-funded policies and programs, and that change with each move. Military social workers comprise one group entrusted to assist with these challenges.

### ***Military Social Workers***

As all other social workers do, military social workers work within programs that are themselves constantly changing. They and the programs are accountable to the interests of individuals and families and to the interests of funding sources, communities, and broader social values. Particularly in the context of services to families with special needs children, individual functioning must be enhanced within the context of limited resources that are shared for a variety of goals and needs. Social work and other service-based professions have moved from devoting resources solely to individuals, but rather to evaluating where, in an ecological context, resources may best be spent in supporting the goals of all involved.

Some of these evaluative functions involve the ongoing assessment of changing needs and service systems. This study is part of a global effort to evaluate the adequacy of existent systems and to identify where needs are unmet, in order to support appropriate prioritization of limited resources. As mentioned at the beginning of this chapter, empirical evidence is needed to support effective program design and policy decisions in order to strengthen the adaptive capacities of both individuals and social services (Rubin & Babbie, 2001). Military social workers accept the challenge to evaluate the broader social contexts within which military families live, in order to assess their relevance to this specialized sub-group. Due to the small numbers of AF special needs families in relation to the entire American special needs' service delivery system, the needs of this group would not be recognized in evaluative research without a particular focused inquiry specific to them. This study is aimed at providing this specific focus. In order to examine how well military families are served by a broader, inclusive system, it is first necessary to describe what that system is, and to identify what the particular needs of military families might be in relation to that system.

### **Statement of the Problem**

Services to families with special needs children have emerged in America from an evolutionary process involving multiple professions, multiple goals, divergent funding sources and competing values. This evolutionary history is described further in Chapter II. The resulting combination of service structures includes public (some means-tested for eligibility, some not), private for-profit,

private non-profit, and geographic-specific agencies, some with a predominantly medical emphasis and some with predominantly educational or social objectives. There continue to be service gaps for some needs, whether due to non-availability or due to difficulty of service navigability.

Given the mobility of military families, and of military service providers as well, both the families and those charged with providing assistance are frequently faced with figuring out another new and complicated system each time they move, for each type of disability or service need encountered. Since many agencies have waiting times for families to access services once deemed eligible, it is conceivable that military families would receive little of the services they need before the child ages out of the system, or the family relocates again.

AF leaders are well aware of these concerns in a national context, yet due to the recent and ongoing changes in service systems and the families themselves, little is known about the current prevalence of specific conditions, of the types of services most desired or pursued by AF families, or of the challenges experienced accessing services after a geographic move. Before AF specific supports can be strengthened in accordance with the goals of the DoD, more must be known about the needs experienced.

The researcher has had several personal communications in 2003 through 2005 with the current subject matter expert for the Air Force, LtCol Patricia Moseley, Ph.D. She is the Special Needs Program Manager in the Office of the AF Surgeon General. LtCol Moseley has expressed the need for current research into service access concerns for these families, and for a descriptive

study of the population and their service utilization. No one military source (e.g., Tricare health insurance records, military treatment facility records), nor any publicly provided service, such as under the Maternal and Child Health Bureau, can provide data about the combination of services pursued specifically by AF families. Civilian services do not identify service recipients by military status.

There has been no comprehensive inquiry to date into the experiences these mobile families have in navigating complex and changing delivery systems. Such an endeavor is desired to support ongoing policy and practice decisions and advocate for the unique needs of military families. LtCol Moseley has further reported the lack of a complete and current assessment at the national level of existing linkages between the military and civilian communities occurring at local levels. She is supportive of proposed research that might address these concerns within a cooperative context, using both university and AF resources.

### **Focus of the Study**

Since so little is known by one centralized source about the current AF population seeking services for their special needs children, this study was designed first to provide a basic description of (a) the families, (b) their children's special needs, (c) the types of services they desire and pursue, and (d) the experiences they report in navigating the complex mixture of public and private services available. Based on a review of the literature (in Chapter II), the study also included an examination of some specific constructs related to service effectiveness and to potential career concerns among AF service members and their families. Given the known variation in service systems across geographic

locations, this study specifically addressed the effect of geographic location on respondents' reported concerns and experiences. By identifying differences based on location, military leaders are more able to target underserved locations and to develop specific support programs based on need. The ultimate goal was to contribute an increased understanding of where additional services are needed, both from a justice perspective and in order to support a strong and healthy AF workforce. The specific questions addressed by this research are presented next.

### **Research Questions**

1. What are the types of special needs currently experienced by children less than six years old who are living with AF families in mainland U.S.?
2. What types of specialized services, provided from which sources (military, private, public), do AF families seek and receive on behalf of their young children with special needs?
3. What challenges do they face in obtaining desired services?
4. What do AF families believe is the impact on the military career of having a special needs child?
5. How satisfied are AF families with the delivery of the services received?
6. How sensitive to military family needs do families perceive their service providers?
7. Do those families who receive services report confidence in their abilities to cope with the demands of rearing a special needs child?

8. How do the answers to these questions vary by the severity of the need, geographic location, by the involvement of a case manager or other available supports, and by relevant demographic factors (such as family income, time in community, or rank)?
9. What do these families say about their experiences pursuing specialized services for children with special needs within a mobile military lifestyle?

Of course, many more questions and research needs can be identified as desirable with regard to this population. However, in order to focus the study, decisions were made that necessarily placed limits on what would be pursued in this investigation. These are summarized below and further described in Chapters III and V.

#### **Limitations of the Study**

While the concerns expressed previously apply to most families with special needs and to military families in general, it was necessary to limit the focus of this research to Air Force families, currently living in selected locations. It is seen as a pilot study, the results of which might support further research into military families' needs, services utilization patterns, and challenges faced. While the results are believed to be indicative of the experiences of a larger number of AF families with special needs children, there is no claim of generalizability to all AF families. This is due to the sampling and participant recruitment methods, discussed further in Chapter III.

There is much more work that could be done to evaluate program and system effectiveness with this population. An inquiry into the satisfaction of AF

families with the services they receive could easily be a stand-alone study. In order not to overburden the voluntary respondents, the decision was made to focus most of the survey questions on the description of needs and services desired, pursued and received (or why not received), as this most basic information is lacking. Information received from this study regarding these and related topics, such as the adequacy of the services or the perceived impact of special needs children on careers, can only be starting points for future research of this type. The literature and theoretical frameworks that guided the development of this study are reviewed in Chapter II.

## **CHAPTER II**

### **REVIEW OF THE LITERATURE**

In order to address the stated research questions, concepts must first be defined and that which is known on the subject surveyed. This chapter presents a brief review of the current state of the literature regarding services to children with special needs and their families. It is presented in these sections: (a) definitions of the identified population, (b) historical background, (c) the current infrastructure of the delivery system, (d) guiding theories, (e) emerging changes in the service paradigm, (f) application of this paradigm to services for Air Force families, and (g) research specific literature. An outline of the subsections incorporated within each of the major sections is presented at the beginning of each section.

#### **Definitions of the Identified Population**

This study purposely focuses on children less than 6 years old (up to 72 months old) who have special needs and live in AF families. It is first important to acknowledge that services to this age group are divided between those serving children birth until the 3rd birthday, and those serving children from age 3 until the 6th birthday. Because of the historical evolution of services to young children involving a wide range of public and private providers, these funding sources and programmatic foci have traditionally distinguished groups of children into (a) birth

until the 3rd birthday, (b) 3 through 5 year olds, and (c) those 6 years old and up (who are likely to be eligible for school-based services) (Bowe, 1995a; Meisels & Shonkoff, 2000).

***Early intervention*** is the term used to represent the wide range of medical, educational, psychological, rehabilitative, case management, and other professional services provided to children less than 3 years old who have been identified with (or who are at risk for) developmental delays or disabilities (American Academy of Pediatrics, 2001; Bowe, 1995a; Malone, McKinsey, Thyer, & Straka, 2000; Oser & Cohen, 2003; Shackelford, 2002). The name itself (early intervention) emphasizes the recognition that the earlier services are provided, the better the expected outcomes in terms of development, school performance and other important measures of child health (Blackman, 2002; Guralnick, 1997; Oser & Cohen, 2003). *Intervention* in the name indicates that active professional involvement is preferred to a passive 'wait-and-see' approach, and that there are key windows of opportunity, or critical periods of brain development, in which interventions are most effective to positively shape a child's physical, emotional, social and intellectual development (Kagan & Neuman, 2000). The current terminology for services to children 3 through 5 is *early childhood education services*, or *early childhood special education*, as compared with *early intervention services* for children birth to 3 (American Academy of Pediatrics, 2001; Bowe, 1995a).

***Developmental disabilities*** is purposely chosen to convey needs of a physical, psychosocial, cognitive, communicative or adaptive nature, or the

presence of a combination of these disabilities, that prevent children from functioning in the same ways as typical children of their same age group (Bowe, 1995a; Brown & Brown, 1993). **Special needs** is even more inclusive, reflecting the full range of conditions or experiences that typically require specialized services in support of functional abilities. Appendix A outlines the administrative guidelines used in the Air Force when establishing the presence of a special need.

**Service delivery system** is used to represent the wide range of programs, agencies, professionals, and services existing across local, state and national levels, which provide professional assistance to special needs children and their families. The diversity of the system is described later in this chapter. Early intervention service systems are among the most complex because of the combination of public and private, for profit and non-profit, medical, educational, preventive and rehabilitative services that comprise these state-based systems (Benn, 1993; Bowe, 1995a).

**Early childhood special education** is used to describe the services offered to these 3 through 5 year old children because they are typically delivered through the public school system (Bowe, 1995a), yet these 'older' children also receive medically related services from a mixture of public and private service entities. Children 6 and older are most likely to have coordinated services and wide-ranging access to services, because services to school-aged children are coordinated by the U.S. Department of Education and its state-level affiliates, or State Education Agencies (Chambers, 1999). For this reason, this

study focuses on children less than 6 years old, the group least likely to receive care coordination through a standardized public system.

Due to the separateness of the early intervention and early childhood special education fields, there is also separateness currently in all aspects of service delivery, including bodies of research. There is also, however, a great deal of overlap between the fields, seen for example in goals, methods, and families served. One area of commonality is the emergence of these fields from the same historical and cultural background, discussed next.

### **Historical Background**

The Education of the Handicapped Act of 1986 (P.L. 99-457) and its successors, the Individuals with Disabilities Education Act (IDEA) of 1997 (P.L. 105-17) and of 2004 (P.L. 108-446), have established the early identification of disabilities and the provision of proactive, coordinated services to young disabled citizens as national priorities. However, this national interest and emphasis is a relatively recent phenomenon, which contributes to some of the complexity and uncertainty in the field. Toward a description of this complexity, it is useful to first situate early intervention and early childhood special education services in their historical context. This section will trace (a) society's changing view of children, (b) the value placed on science and its application to improving life, (c) the merger of medicine and education in this field, to include separate descriptions of the evolutions of American medicine, of American education, and of services to young children, (d) ongoing debates that continue the historical evolution, both

ethical and pragmatic, (e) political processes which influence history, and (f) the result from all of the above: a mixed, fragmented system.

### ***Society's Changing View of Children***

Western society has witnessed a change in its view of children and of the value of their social position. For example, children of Western Europe and the nascent United States (pre 1700s) were typically not afforded any protective status (Popple & Leighninger, 1998). Adults did not view their own actions as being directly responsible for whether children lived, or not. Child mortality rates were so high, over 50% in England prior to 1800 (Eisenberg, 1981; Garbarino & Ganzel, 2000) that their survival seemed a matter of chance, left for fate to determine. Children who lived were considered the property of their families, or those who accepted responsibility for them; they were not viewed as having any social privileges or rights of their own.

The purpose for having children at that time was to contribute to the economic security of the family and a small, homogenous community. Their value was in their ability to produce, and those who were not likely to produce well due to physical or cognitive impairment were either minimally maintained or abandoned to die (Bowe, 1995a; Eisenberg, 1981; Logan, 1979). When assistance was provided, it was likely provided by the church or other religious groups, compelled by charitable motives (and a desire of the giver to obtain heavenly rewards). It was therefore intermittent, unpredictable, and unchallengeable. No one was charged with responsibility for the welfare of

children, as there was no perceived need for such protection (Popple & Leighninger, 1998).

Several interacting historical factors interacted to change western perceptions of the child beginning in the 1800s, including the Industrial Revolution. Children were no longer necessary to produce the goods of daily life (although they certainly did well into the 20<sup>th</sup> century). A new concept of the child included an investment in future potential (to labor, to marry, to attain status as a business owner, etc). Combined with public health and labor initiatives of the early 20<sup>th</sup> century, the need for protection and for social intervention into the family emerged (Karger & Stoesz, 2002; Popple & Leighninger, 1998).

Because of the Industrial Revolution, the urbanization of America, and the mobilization of labor resources for the world wars, a need was generated for childcare that was provided outside of the home (Seefeldt, 1980). The professionalization of childcare and the detachment of parents as the sole authorities over children brought new perspectives. One aim of early childcare centers was to socialize immigrant children into American customs and mores: to minimize the influence of incompetent parents and to allow agents of society to shape the proper course for the child (Seefeldt, 1980). The child emerged not merely as a family asset but as society's investment in its own future. With this changing concept came increasingly recognized rights of society to intervene in families regarding the welfare of children (Karger & Stoesz, 2002). As children became valued socially, society framed its claims against families for their proper upbringing (Popple & Leighninger, 1998).

However, society as a whole has never chosen to assume total responsibility for producing and rearing children. The special role of the family as the primary vehicle to produce functional citizens continues to be sanctioned today—and families continue to bear most of the financial costs of raising children (Popple & Leighninger, 1998). Yet, due to these philosophical shifts, families now place expectations on outside social agents to support them when rearing the children. If the needs of children exceed families' abilities to care for them, families expect assistance from the local community and from larger governmental sources. Claiming its interest in the welfare of children, society has accepted this role in many forms. In fact, the provision of this assistance became viewed as one of the hallmarks of a civilized and democratic society, exemplified in some of the social policies of the New Deal (Karger & Stoesz, 2002).

The federal government provided widespread financial assistance (and therefore assumed some responsibility) for many of the vulnerable populations of American society. The supportive role of the federal government with regard to children began in 1912 with the establishment of the Children's Bureau in the Department of Labor, and continued through the Social Security Acts of 1935 into many other major programs well into the 1970s (Karger & Stoesz, 2002; Meisels & Shonkoff, 2000).

These developments indicate an evolution from the view of children as property, their fates left to chance, to a recognition of children as valuable social assets for whom government assumes a responsibility to protect and support. They also indicate the ongoing balancing act between families, local

communities, and larger societal structures in determining who has ultimate responsibility for the welfare of children (Bowe, 1995a; Harbin, McWilliam, & Gallagher, 2000). Cultural norms regarding society's approach to children continue to change over time, affected by multiple influences. Among these, the possibilities generated by science and technological advancements must be addressed.

### ***Value on Science and its Application to Improving Life***

As American society shifted from an agrarian to industrial focus, the role of science and technology was elevated. In 19<sup>th</sup> and 20<sup>th</sup> century America, science and its application to social wellbeing took center stage. This shift can be seen in the rapid development of both medicine and education, two fields from which services to young children have evolved. Americans looked to science to explain health and behavior rather than believing in spiritual or metaphysical explanations; we continue to have faith that science will eventually solve (nearly) all the problems of life (Popple & Leighninger, 1998). Medicine and its practitioners were elevated to authority status, often above the spiritual leaders and landowners that had previously ruled society (Conrad & Schneider, 1980).

Science also extended its reach into advancements in education, through the blossoming fields of psychology, sociology and child development. Early childhood education and related programs, such as the development of nursery schools in the 20<sup>th</sup> century, were designed based on the growing knowledge of child growth and development (Seefeldt, 1980). Scientific advancements in both medicine and education were sought and applied toward the goal of an

enhanced society (Popple & Leighninger, 1998; Read & Patterson, 1980). Some of these scientific advances resulted in the development of theories that are still used today in examining individual and social behavior, in designing human services, and in shaping societal goals.

### ***The Merger of Medicine and Education***

The current state of the field of early intervention and early childhood special education may be viewed as a partial merger between medicine and education. However, there are significant differences in the premises, goals and delivery methods of medicine and education in this country. This is due in part to their distinct historical evolutions, discussed next.

### ***Evolution of American Medicine***

Decisions were made in America to retain medical advancements and services in the private sector, where free market economics and the values of capitalism drive many decisions (Popple & Leighninger, 1998). As medical researchers and practitioners became able to explain and predict health conditions, they were elevated to authority status and became *owners* of this knowledge. Medical care became viewed as a privilege, granted by the private owners who were entitled to profit from its sale. Access to health care became based on one's ability to pay for it, either through private insurance or public assistance (Litman & Robins, 1984; Popple & Leighninger, 1998).

Due to the persistent myths that have surrounded poverty and the stigma of being poor in America (Karger & Stoesz, 2002), society has accepted limitations on levels of medical care provided to the poor (Popple & Leighninger,

1998) and a standard of care based on what can be afforded. Additionally, those who are seen to have caused their own problems (through alcoholism and other drug abuse, or reckless behavior) frequently experience severe limits on the level of care offered through public sources (Jansson, 1984).

### ***Evolution of American Education***

Education, on the other hand, developed as an entitlement, partly due to the capitalistic and scientific history of America. With advancements in the ability to measure cognitive functioning, or IQ (intelligence quotient), came the application of this technology to purposefully sort the *feeble-minded* from other children, in order to enhance the efficiency of the school system and to predict potentials for achievement (Stevens & Wood, 1987). The ultimate benefit to this capitalist society (in an era of increasing global competition) was seen as the ability to select which training methods and settings are best suited for each group in order to maximize their productive capabilities. Thus education became the vehicle to produce human capital, toward the common societal good (Stevens & Wood, 1987).

Others, however, challenged this capitalist view as the sole purpose of education, and saw education as the means for the development of responsible citizens. In the late 1800s, this took the form of transmitting ideological messages through schools to immigrant and poor children to establish good work habits and to avoid the problems of poverty; figures such as Horace Mann influenced these early years. As the political climate later extolled the vices of Marxism, communism and socialism, public schooling advocates argued that democracy

depends on self-governance, which requires knowledgeable people experienced in shared decision-making. John Dewey was a prominent figure during this era that continues to influence this perspective on education. However, the advent of the Cold War rocketed American educational advocates into an emphasis on scientific and technological skills (Stevens & Wood, 1987).

Yet each of these concepts of the purpose of schooling contributed to a national push for ownership of schools by the state. Prolific federal legislation was enacted (e.g., *Brown v. Board of Education of Topeka, KS*, 1954, and *Pennsylvania Association for Retarded Children v. Commonwealth of Pennsylvania*, 1972), which cemented education as an entitlement for all children (Bowe, 1995a). The specific intention of education was to equalize opportunity and to maximize the potential of all Americans, regardless of income, race, or ability. Because of these contributions of certain figures and of the prevailing philosophies of an influential time period in the formation of the current educational system, Americans now view public education as a right of citizenship, not a privilege afforded to the affluent (Read & Patterson, 1980; Stevens & Wood, 1987).

#### ***Evolution of Services to Young Children from Both Medicine and Education***

Historically, early intervention/early childhood special education became administratively framed as educational programs, due to the way that advocates for the disabled made their claims for redress through educational legislation (using a model that was successful for black Americans in the civil rights' movement). Disability advocates used prevailing beliefs about education as the

source of opportunity to demand assistance and protection from the federal government (Bowe, 1995a; Mary, 1998). Early intervention and early childhood special education grew from the recognition that equal opportunity for the disabled in school depends on proactive identification and treatment of disabilities, as early as possible (Meisels & Shonkoff, 2000; Peterson, 1987).

However, the services that disabled children need in order to benefit from educational opportunity are typically medical in nature. This is especially true for very young disabled children (the particular clients of early intervention and early childhood special education *per se*). Identified needs of children from birth to five are not likely to be solely educational in nature, as might be true for older children. They are more likely to be the result of physical disabilities that are likely to impair educational success later in life. This type of need is served in America by the medical system.

Thus, in order to access an entitlement (education), disabled children are dependent on a service viewed as a privilege (medicine) for which their access may be constrained. This dilemma has contributed to the emergence of a service delivery system that necessarily relies on a convergence of two distinct fields with very different service structures. Melding the two has been a challenging process, filled with debate over goals, eligible populations, funding mechanisms, and responsibilities. Some of these are discussed next.

#### ***Ongoing Debates, Ethical and Pragmatic***

The current debates surrounding public support of early intervention and early childhood special education services in America do not generally focus on

*whether* to provide social assistance to this group, but rather on *how* to provide assistance, *how much of what type of assistance* is required by society, and what level of society (or *who*) is responsible for the provision of assistance. Thus, it is not the ends that are in question, but rather the means (Freeman, 2000; Gallagher, 1989; Loewenberg, Dolgoff, & Harrington, 2000).

Critical questions have emerged regarding how much intervention (medical care, assistive devices, etc) and of what types are truly needed. Further debates surround how they should be provided by whom, where they should be provided, and how much is needed to allow equal educational opportunity (Bowe, 1995a). The appropriateness of intervention for each child's need reflects the *adequacy* of the system; the fairness of distribution of services across all children and their needs depicts the *equity* of the system. Typically, each is reduced by attempts to maximize the other (Chambers, 1986). Quickly an impasse is reached in the debate because of the many levels of claims represented, from professionals, families, local, state and federal governments, and other funding sources, each with a different interest in the outcome (Karger & Stoesz, 2002). Research documents that the earlier and the more intervention, the better the outcome (Bowe, 1995a; Guralnick, 2001; Kagan & Neuman, 2000); but funding sources are not limitless and decisions must be made regarding how much is enough given other social priorities (Gallagher, 1989).

Due to rapid progress in technological advancements for early intervention and early childhood special education services, the expense of providing the care that is now possible and expected exceeds society's ability to equitably provide it.

Allocation and distribution dilemmas arise from limited resources, from competing values regarding the public interest vs. the common good (Freeman, 2000) and from the seemingly irreconcilable claims of separate interest groups (Karger & Stoesz, 2002). Decisions are required of families, professionals and of social policy makers that confront conflicting values and competing claims for limited resources (Gallagher, 1989; Loewenberg, Dolgoff, & Harrington, 2000). When caring and autonomy or liberty are valued highest, localized services are desirable. When justice and the common good are valued highest, larger and more inclusive levels of government are best equipped to meet the demands.

Technology allows limitless options and the question has become "how to decide what ought to be done" (Loewenberg, Dolgoff, & Harrington, 2000, p. 6). These decisions are made through a competitive and deliberative political process in the United States (Karger & Stoesz, 2002).

### ***Political Processes***

The political considerations of this issue are not distinct from the historical, philosophical, and economic contexts within which they exist. Due to the dynamic interplay of all of these social forces, the allocation of shared resources is especially challenging—and this is the task of the political system. Different levels of political society have different access to resources. One of the dilemmas inherent in the early intervention and early childhood special education policy debate is determining the appropriate level of political action to address the delivery of services (Gallagher, 1989). A duality exists within the American political system in the balance of federal and state powers. Each is reluctant to

surrender rights or benefits it had previously enjoyed to the other (Karger & Stoesz, 2002). This territoriality is played out in numerous proving grounds, and education and medical funding are two enduring arenas for these contentions.

Best (1995) provided a review of how certain claims against shared resources are met with success in American society. He pointed out that claimsmakers transform a situation into a *need*; the more personal, the better. This is similar to Janssen's discussion (1984) of the relativistic viewpoint of ethical decision-making, emphasizing that all parties are likely to act from self-interest. When a situation that affects me or might affect me is framed by claimsmakers as a need, I am more likely to respond to the claim, whether as an individual citizen, a potential donor, or a legislator. American political history and particularly national health policy have been greatly influenced by the power of special interest groups (Litman & Robins, 1984).

This is true regardless of the political divisions that exist. Both liberals and conservatives act from their own interests; what differs is how they prioritize competing claims and interests of the common good and the public interest. This prioritization results from differing emphasis on certain individual and community values (Dokecki, 1986; Karger & Stoesz, 2002; Loewenberg, Dolgoff, & Harrington, 2000). Among these values are (a) freedom from outside interference (liberty), (b) localized, self-governance (autonomy, self-determination), (c) a commitment to serving or helping others (beneficence), (d) the importance of fairness and equality (justice), and (e) the recognition of external causes of disadvantage and oppression (compassion and mercy) (Freeman, 2000;

Loewenberg, Dolgoff, & Harrington, 2000). Few legislators or other policy developers would say that any one of these values represented in the debate is unimportant. But every claim satisfied represents another one that cannot be (Karger & Stoesz, 2002).

Liberals (neo-liberals, Democrats) tend to favor centralized, mandated federal legislation and funding that maximizes early intervention services as an entitlement to anyone with an identified deficiency or risk factor. They tend to view the common good as best served when every child has equal access to equal levels of service, and the federal government as the only level with the legal and financial power to make this happen. Many of these people believe that legislation mandating early intervention services was accomplished in a fair and pluralistic approach to policymaking (Popple & Leighninger, 1998). They argue that subtle or discrete funding maneuvers that occur in the federal appropriations process and which detract from these services betray the voice of the people (Karger & Stoesz, 2002).

Conservatives (neo-conservatives, Republicans) tend to emphasize states' rights in deciding appropriate service levels, and want private or local agencies to provide services that will address the uniqueness of each region's needs. They tend to view the public interest as requiring lower federal taxes (taxes that would be needed to support a universal entitlement) in order to maximize the local ability to respond to their own needs and priorities. Proponents of this viewpoint, the *public choice* method (Popple & Leighninger, 1998), believe that privatized social services will be more efficient because of the

competition in free markets, and that people will actually give more if it is voluntary giving and the benefits are seen in their own communities (Karger & Stoesz, 2002).

For some, this debate turns into a concern about an apparent widening in the class divide, believing that political power is increasingly vested in the rich who turn a deaf ear to the needs of the growing poor. These opponents of the elitist model (Popple & Leighninger, 1998) of policy development lament the apparent attrition of rights gained in the 1960s and 1970s, seen in the current devolution of federal social programs (Magrab, 1999). Some claim evidence of this in the increasing frequency of federal block grants to states, a process which ultimately results in fewer federal dollars given each state and increased variability across the country in important programs (Popple & Leighninger, 1998). These debates are just a few of the many that are exemplified in the political process regarding social welfare policy in general, and early intervention/early childhood special education policy in particular.

### ***The Result: A Mixed, Fragmented System***

The fields of early intervention and early childhood special education are still evolving within these historical and political contexts, and are relatively new fields. Attempts to resolve these ongoing debates and conflicting values through political processes have thus far resulted in a service delivery system that varies by location, that combines means-tested eligibility determinations for some programs with universal entitlements for others, and that is delivered by a wide range of agencies and professionals with varying goals and methods. All are

guided by federal legislation under the Individuals with Disabilities Education Act (IDEA), as well as by national and state health policies, such as through Maternal and Child Health (Title V of the Social Security Act), Medicare, and Medicaid programs. However, a great deal of variation is permitted and encouraged at local levels (Bowe, 1995a; Harbin, McWilliam, & Gallagher, 2000; Mahoney & Filer, 1996). The following sections present the current structure of the delivery system that has emerged from the historical background of services to young children, including the current legislation. This is followed by a review of the components of service delivery that are standardized and universal, and those that are variable. The funding of these various components, however, is a separate matter contributing much to the variability seen in multiple levels of the service delivery system. This is discussed in subsequent sections.

### **Current Infrastructure of the Delivery System**

This section reviews the foundations of the current infrastructure of the delivery system for young children with special needs: (a) the federal legislation which enforces it, (b) distinctions between federal and state roles, (c) state discretion, resulting in state based variability, and (d) the unfunded mandate, which includes subsections that further describe combinations of funding sources and competing claims regarding levels of fiscal responsibility. This description is critical toward emphasizing the particular difficulty of military families as they access services from multiple states in a short time frame.

### ***Federal Legislation***

Early childhood special education and early intervention are prescribed by federal law to a remarkable extent. The exact wording of statutes in this arena is seen as more important to the structure and delivery of services than in general education or in general early childhood fields (Bowe, 1995a). In both policy and practice in the U.S., early intervention and early childhood services/special education are specifically and separately designed for children birth through 5. The U.S. Department of Education has commendably shaped a comprehensive package of services that is provided for older children with special needs in the context of the public school system. However, given the importance of identifying disabilities and intervening in the earliest years of life, federal policy makers in 1986 added portions to the Education of the Handicapped Act (EHA, originally P.L. 94-142, amended under P.L. 99-457 in 1986; it became the Individuals with Disabilities Education Act, or IDEA, in 1990 via P.L. 101-476, the 1997 version is P.L. 105-17, and the 2004 version is P.L. 108-446). The new portions that encouraged services to the very young (birth until 3) became known as Part H under the EHA. When the IDEA was amended in 1997, the sections that pertain to children from birth to 3 became known as Part C services, and those for children 3 through 5 became known as Part B (Hanson & Bruder, 2001; Harbin & Danaher, 1994).

The goals for all of these *carve-out* portions of the legislation are the same: to promote early identification of risks and disabilities, and to support the development of a service infrastructure designed to enhance the outcomes for

these children in preparation for the developmental tasks of later childhood. This legislation has continued to be supported in subsequent reauthorizations due to an emphasis on reducing future educational costs and preventing expensive institutionalizations (Dokecki & Heflinger, 1989).

#### ***Distinctions between Federal and State Roles***

A balance has been negotiated in federal legislation and regulatory guidance between the separate roles of the federal government and the states. Bowe (1995a) reported that the federal role has been defined as (a) setting requirements that programs in states receiving federal funds must meet (all states currently do) including the types of services are allowed, which costs are permissible to pass on to families, and the like, (b) monitoring, providing funds for training, demonstration projects and research, and (c) providing coordination at the highest levels, for example between the Departments of Education and of Health and Human Services. He further held that the states' role is to (a) select a lead agency to coordinate services within each state, (b) establish eligibility guidelines, (c) create a directory of services, (d) maintain a database about the use of services and the number of children who meet the established criteria for services, (e) provide child find and public awareness initiatives, (f) establish procedural safeguards, (g) establish guidelines and programs for personnel preparation, and (h) ensure the provision of direct services.

Bowe then claimed that the local role, within communities, is paramount (1995a). This is where children and families actually receive the services and

where negotiations occur between the separate programs and their funding specifications for eligibility.

### ***State Discretion and State Based Variability***

The result of this level of differentiation in structures and responsibilities is that there are 50 plus (including U.S. territories such as Puerto Rico and Guam) separate policy and delivery systems regarding early intervention and early childhood services at work in the U.S. today (Goetze, Andrews, and Greer, 1999). Everything from the determination of what constitutes a disability to which professionals will be reimbursed varies from state to state (Benn, 1993; Brown & Brown, 1993; Harbin & Danaher, 1994; Shackelford, 2002). The methods for accessing diverse resources vary at local and state levels. Some programs require individual family application, some are accessed by agencies applying at the community level who then serve a targeted group, and some funding sources are accessed only at systems or state levels (Goetze, Andrews, & Greer, 1999). An unintended consequence of this variability, it has been argued, is that only resourceful families get the resources (Akers & Behl, 1999), leaving many concerned that neither adequacy nor equity are provided under this entitlement.

States provide many of these services under federal mandate in IDEA, Parts B and C. States are only partially supported with federal funds to provide these services; considerable latitude regarding how the services are designed and implemented is left to individual states (Meisels & Shonkoff, 2000; Shackelford, 2002). Each state and U.S. territory funds these services at different levels, and each maintains separate standards regarding eligibility for, and

provision of, publicly provided early intervention and early childhood special education services (Hanson & Bruder, 2001; Shackelford, 2002). Additionally, different communities offer specialized services from a range of varying private non-profit and for-profit (insurance based) agencies.

States make the determinations regarding the definitions of special needs, eligibility for services, access standards, which types of agencies take the lead in coordinating services (e.g., health care or education), which types of professionals will provide which services, and reimbursement rates. States determine which categories of need will take precedence in service delivery decisions, such as severity of physical disabilities, presence of emotional or behavioral disabilities, environmental conditions or risks, and financial status (Benn, 1993; Harbin et al., 2000; Shackelford, 2002). As might be expected, wide variations exist across states in the early intervention and early childhood special education delivery system. Many children who would be eligible for intervention and assistance in one state are not in another. The types of services provided and the intensity or length of those services vary across states and even across regions within the same states. These variations make frequent geographic relocation extremely challenging for military families. Expectations for services enjoyed in one state may place unrealistic demands on the resources of a different state when federal employees are transferred. States themselves have widely varying levels of the resources necessary for providing services.

### ***The Unfunded Mandate***

The Individuals with Disabilities Act, or IDEA, recently reauthorized at the federal level in 2004, directs the provision of special services from a federal level. However, since its inception, overall federal financial support for educational services to disabled children has only been 8% of the actual costs—states make up the difference (Parrish & Wolner, 1999). This is discussed in the field as an unfunded mandate, and generates numerous challenges for practitioners in meeting the letter of the law within budgets that are not solely devoted to early intervention or early childhood special education. Similarly, federal health care funds which support the medically-related aspects of service delivery (such as through Medicare and Social Security) are increasingly provided through states as block grants, leaving states to determine how much will actually be allocated to the care of special needs children (Nathanson & Ku, 2003).

### ***Combinations of Funding Source and Services***

While legislation outlines the requirements, how the services are funded drives the structure of the system to a large degree. Which services are available in different locations typically vary according to who is paying for them. A 1983 quote by M. Joseph, cited in a recent social work ethics textbook, stated that “ethical concerns are generated by the structural and interactional arrangements of organizations, as well as from their goals and objectives” (Loewenberg, Dolgoff, & Harrington, 2000, p. 16). This is nowhere more true than in the early intervention and early childhood special education systems, living both within education and medicine.

Within the educational perspective and supported by federal legislation, all children regardless of income or disability are to be offered a free and appropriate public education (Bowe, 1995a). Yet the types of services needed by disabled children in order to participate in public education include rehabilitative and occupational therapies, attended nursing care, adaptive equipment, and many other services offered as medical care. Medical care is provided by private sources, and children compete for constrained public resources with all other age groups within tightly controlled public funding mechanisms (Popple & Leighninger, 1998). Therefore the types of services needed by the youngest children are typically funded by private insurance to some degree, and largely by community and state level programs (such as Medicaid). Within this service sector there is a mix between universal entitlements (such as for services under the funding provided to states for early intervention in Part C of IDEA, offered without regard to income) and means-tested services (such as Medicaid's Early and Periodic Screening, Diagnosis, and Treatment program or EPSDT) (Bowe, 1995a). Again, even though the *impetus* for service comes from a federal level and from concepts of universal opportunity enhancement, the *delivery* of service is financially supported by state or local agencies that combine disability needs with financial needs in eligibility determinations. This delivery system is typical of the mixed welfare economy in America (Karger & Stoesz, 2002). According to Hanson and Bruder (2001), funding has become the driving force of service design and delivery, versus programmatic goals or beneficiary needs.

The tensions among those competing for state or local resources are escalated with the devolution of federal social spending (Karger & Stoesz, 2002). Block grants that place services for disabled youth and the elderly (among other vulnerable populations) in the same dwindling budget bring forth the competing claims of equally deserving populations. Thus medical funding policy, evolved from the juxtaposition of (a) concepts of economic privilege generated by capitalism, and society's view of one's *worth*, within (b) a delivery system that strives to be the great equalizer (education), creates ethical and pragmatic dilemmas for those engaged in early intervention and early childhood special education systems. Those responsible for providing education within a limited public budget understandably resist allocating funds to services viewed as medical care. This leads to a further discussion of the difficulties for early interventionists in determining who should be responsible for which aspects of service.

#### ***Competing Claims Regarding Levels of Fiscal Responsibility***

Deontologists and teleologists alike agree that helping disabled children reach their potentials is a worthy cause: caring for life and promoting human potential is an absolute good, and intervening early in physical or cognitive disability is cost effective and beneficial for society. Yet proponents of both perspectives are split regarding the appropriate locus of the required decision-making. At the heart of the issue is who will assume the financial responsibility for decisions made about the welfare of these children, or along which lines will levels of society divide which responsibilities (Karger & Stoesz, 2002).

Whereas the provision of education was established in the Constitution as a right of individual states, disability rights advocates challenged that the manner implemented by the states was discriminatory. Efforts to amend education at the state level were unsuccessful, and the concern was elevated to the national level. Landmark federal legislation was passed based on this view of education as a public entitlement and of separateness of schools being inherently unequal (Bowe, 1995a; Mary, 1998). However, states retain the right to shape educational services for all other children, with federal supports for the education of the disabled superimposed (Goetze, Andrews, & Greer, 1999). Each points to the other as the proper source of funding for early intervention and early childhood special education services. This is particularly true as state-based service systems seek compensation from federal entities for services rendered to military families.

Currently a delicate balance exists between the two levels of authority. As federal block grants and mandates provide support but leave discretion to the states, competing claims escalate regarding what constitutes the right amount of intervention that should be publicly funded, and who is responsible to finance it.

It is useful to apply some well-known theories to these dilemmas in order to consider how best to address them. Those described next represent the major guiding theories of the researcher in conceptualizing and operationalizing the research undertaken. First, the systems/ecological perspective will be described as a major foundation of this research, with other related and contributing theories subsequently examined.

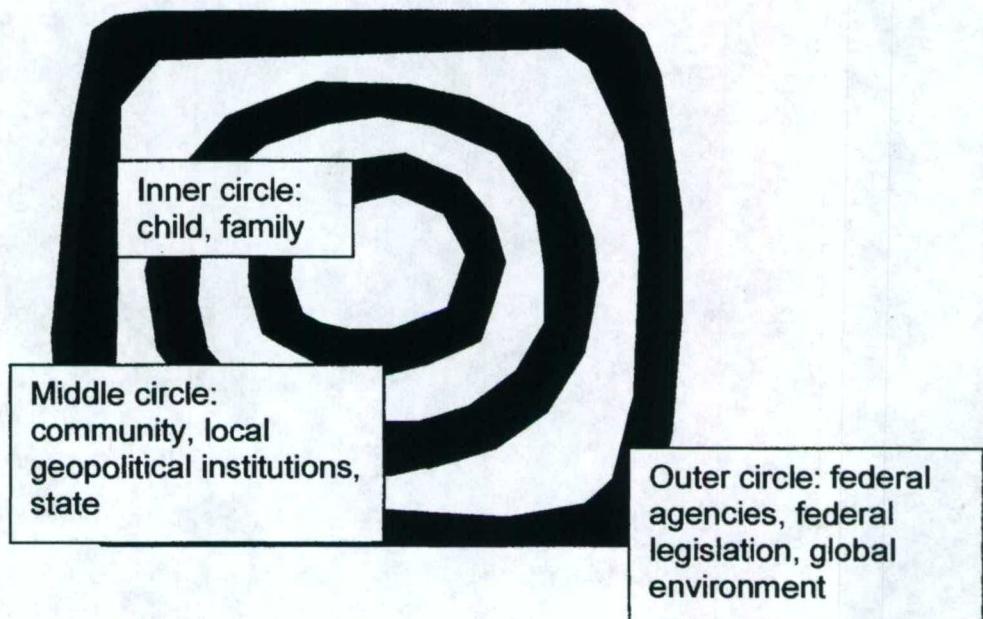
## **Guiding Theories**

Theories and models of social behavior are useful when examining such complicated macro-level systems and processes. Those chosen for application to this study are elaborated in this section: (a) the systems perspective and ecological context model, (b) exchange and social network theories, (c) humanist theory and developmental theory, to include the concept of plasticity, (d) the strengths perspective, (e) stress theory, and (f) role strain. These guiding theories are not seen as mutually exclusive, but rather each grouping presented is significant enough to present in its own section. Each is seen to elucidate a particular aspect of services to families and of families using services, establishing the premises of the research undertaken.

### ***The Systems Perspective and Ecological Context Model***

General system theory (von Bertalanffy, 1968) and systems theory are paradigms that help to examine the many levels of decision-making regarding shared goals and resources that must co-exist. For this study, structural functionalism, neofunctionalism, and Andersen's Behavioral Model of Health Services Use (1995) are presented as subsections of the systems perspective or of systems theory. Systems theory became popularized and applied to social situations from the original concepts developed around mechanical or natural processes (von Bertalanffy, 1968). Recognition of the interactive nature of systems and subsystems and of the transformation effects of the informational flow between them is seen in the subsequent ecological model of Bronfenbrenner (1979), and in the person-in-environment model (Karls &

Wandrei, 1994) used extensively in social work. These concepts are frequently pictured in concentric circle diagrams (Figure 1).



**Figure 1. Ecological context of early intervention.**

This model (adapted from one used by Roberts, 1999, with permission cited from Roberts, Rule and Innocenti, 1998) is particularly useful in depicting the mutual obligations of the individual to the society, and of the society at various levels to the individuals and sub-systems within it. No system or level can function separate from the influences of the others. Mid-level systems or circles serve both as a funnel of information and resources (from lower levels up and higher levels down), and as a buffer constraining the potential of larger systems to coerce or ignore the smaller systems or subsystems. The largest sections of society are responsible to the individual; and vice versa. In a sense, the mid-levels balance the obligations and claims of each to the other. When local levels are unable to provide for all members, claims are made against the higher levels

for the benefit of all included. When a larger entity cannot realize decisions that involve specialized considerations, these are then passed down to a lower level for implementation. Thus all take responsibility for the ongoing negotiations and consensus required in making decisions.

Consensus theories, such as structural functionalism (Ritzer, 2000) are used to describe this process of orderly differentiation, balance, and negotiation. The difficulties arise when the values and claims of one level are in conflict with another. Then conflict theory (Ritzer, 2000) may be more useful in explaining the social upheaval and change that occurs. An example of this was seen in the 1970s when disability advocates challenged the existing system and the ability of states to equitably serve all children. The federal government concurred, yet states vehemently protected their constitutional rights to provide for the education of their citizens without federal interference. The result of this conflict was a new organizational structure regarding the delivery of education to the disabled (Meisels & Shonkoff, 2000).

### ***Structural-Functionalism***

Structural-functionalism is seen for this study as a more specific form of systems theory that examines the division of roles and the levels of specializations necessary in a complex society (Ritzer, 2000). Higher levels are necessarily more general in order to encompass all that are within; as the complexity of any function increases, the system must differentiate into smaller subsystems that are able to provide the needed specificity. The parts of the system exist within an order, and are interdependent within the broader system.

In order to maintain equilibrium, the higher levels of the system are involved in allocation (for example, of resources) and integration (facilitating interactions among the interdependent parts).

Ritzer (2000) further described the work of Parsons in structural-functionalism with the emphasis on the motivation of all parts to optimize gratification of needs for its members. As the needs exceed the ability of any system or subsystem to meet them, then the function is reallocated: either to a higher system (for example, if more resources are needed) or to a newly differentiated, lower subsystem (where more specificity is needed).

State level social services may be seen as a sub-system of the federal system, for example with regard to the flow of regulatory guidance and funding for early intervention. However, federal employees such as those in the military receive most of their direct services from state and local entities. There is no early intervention system for military families that is separate from the civilian subsystem, which is itself a sub-system of larger educational and health care delivery systems embedded within states. Structural-functionalism helps to depict this concept in that, while states are a subset of the federal system structurally, when the function of early intervention is the focus, then the federal service delivery system for military families is actually a subset of the existent state systems. The identification/case management/information and referral services that exist solely for military families is actually a subsystem (for specificity) of the state and local delivery structures, even though geographically it extends between states and is supported directly by federal funds.

As further described by Ritzer (2000), Parsons recognized that differentiation leads to enhanced functioning and this is termed adaptive upgrading. However, with adaptive upgrading comes a new challenge, that of integration. The current early intervention/early childhood special education delivery system for military families is seen as an adaptive upgrade, but due to the challenges of the dynamic regulatory and fiscal environment that exists within each state, integration has been challenging. The effect on military families can be seen when a subsystem (the military specific information and referral system) is not yet properly linked to the delivery system of the state that has the needed resources. Needs and available resource do not always connect.

### ***Neofunctionalism***

Neofunctionalism as proposed by Merton, Alexander, and Colomby, discussed in Ritzer (2000), helps to explain these phenomena: not all structures are functional. Whereas Parson's concept of structural-functionalism includes the concept of functional unity, Alexander points out that as social change occurs in differentiation, this change does not always produce conformity and harmony. In fact, according to Alexander (1985, as cited by Ritzer, 2000), sometimes individuation and institutional strains are experienced. Merton, in the same source, is credited with the concept that one subsystem's adaptation can have negative consequences for another, and that adjustment is not always positive for all subsystems as might be implied in structural functionalism. To Parson's credit, his view of evolving society is probably much more long-term in nature, whereas the *institutional strains* and dysfunctions described by Alexander (and

currently noted in the early intervention/early childhood special education system) that are experienced at one point in time will be resolved, in some way, over time.

### ***Behavioral Model of Health Services Use***

Any group that is interested in resolving these strains and disconnects must, of course, examine the multiple levels, systems, and factors involved in this complex concern. This step flows from a broad theoretical understanding of system or consensus theories, to a review of consistent models which describe how impacting one or more subcomponents may change a larger system. One model that may be particularly applied to the dilemma of military families in accessing early intervention services that they may be eligible for is Andersen's Behavioral Model of Health Services Use (Andersen, 1995). Initially developed in the late 1960s, it has been updated over the development of the health care delivery system and has, itself, become more complex and differentiated with the parallel processes in society. It is acknowledged here that, while designed to explain access and utilization of health care specifically, the nature of the service delivery system for young children with special needs that is dependent on health care services in order for the education portion to function, permits application of this model in many ways.

To simplify it here, Andersen (1995) presented several major contributors to the outcomes of the delivery of health care services. Outcomes listed are perceived health status, evaluated health status, and consumer satisfaction (which link directly to the DoD Quality of Life goals). The major contributors to

these outcomes, according to Andersen and elaborated much more fully in the cited article, are the environment, population characteristics, and health behavior. The pictorial depiction of the model shows many feedback loops and other connective mechanisms among and between all the parts, fitting it nicely into a systems paradigm or a structural-functional approach. This model may be used whether the goal is to restrict or control access (as with some cost-containment strategies) or to enable more effective and efficient access, as is the case with military families who have special needs children. In the presentation of his model, Andersen (1995) discussed his definitions of both effective and efficient access, and both include elements of improved consumer satisfaction. This, then, is a key tie between the model and the DoD goals for its beneficiaries.

Within Andersen's depiction of the major contributors to health care outcomes, including satisfaction, are multiple factors and influences, consistent with structural-functionalism's differentiation. Also consistent with systems theory and structural functionalism, impacting any of the parts or subsystems within this model will affect the overall system, or functioning. This provides hope for those concerned for military families who are challenged by the current service delivery structure. This structure has evolved from policies and philosophies that, for example, limit government intervention, place limits on entitlements, and delegate significant roles to states and localities resulting in great inequities. Yet there are areas which can still be addressed toward serving families.

Andersen encourages those interested in changing health outcomes to determine which factors are the most *mutable*, or within the control of the change

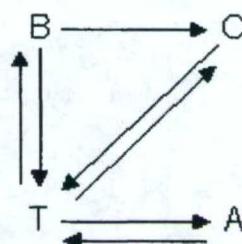
agent. Whereas demographic characteristics of beneficiaries and broad social structure aspects of the service delivery system are likely not mutable by military family advocates, the local environment(s) and small group health behaviors might be. These could be done via strengthening, or differentiating, local, community based enabling resources specifically tailored to military special needs families. The military service delivery subsystem, couched within the broader delivery system, may maximize its role through the use of its own enabling resources in the areas of information sharing (such as electronic information storage and transmission networks, and military family support groups). These and the specialized information resources of other interested parties are all currently in the process of adaptive upgrading (term credited to Parsons, as cited by Ritzer, 2000). Foster and Foster (1993) specifically identified the quality of the case management role as significant in promoting or prohibiting early intervention service utilization. Seen as mid-level, integrating functions, these information-sharing and support roles may be among those that are most mutable by military leadership. Still within a systems theoretical framework, the properties and benefits of this information sharing and localized supportive interactions within the military community are viewed within a social exchange theoretical framework, described next.

### ***Exchange/Social Network Theories***

The importance of community based enabling resources in supporting families is long embraced by the military community. A useful model for understanding this phenomenon is found in social network theory, with important

understandings provided by exchange theory. All individuals and families are seen as existing within social networks of relationships. These relationship patterns emerge from repeated interactions with, for example, others at work, with extended family members, neighbors, and professional service providers. Every person's pattern of social interaction may be represented in a social network diagram or *map*, which displays these linkages in terms of the ties between and among people who interact with other.

In Figure 2, for example, T could represent the parent of child A. T is also in relationships with her own parents (B and C), who are in a relationship with each other. The simplistic representation shown would actually become more complex as other relationships (such as three-generational relationships, co-worker, and neighbor relationships) are added to the diagram of social networks experienced by T. All are believed to affect the parent-child relationship, either directly or indirectly.



**Figure 2. Example of social network map**

(<http://faculty.ucr.edu/~hanneman/SOC157/TEXT/C3Graphs.html>).

While this type of depiction of relationships may seem similar to genograms or other methods used to examine relationships, it is important to

note that a social network map is a necessarily static representation of a temporary situation, a snapshot of an actually dynamic process. Social networks are constantly in flux and are in large part determined by the amount of information sharing and/or emotional connectedness experienced between people at any given time.

Wikipedia (2005) nicely described why these concepts are useful in examining how or why people find and use health or other services the way that they do.

The power of social network theory stems from its difference from traditional sociological studies, which assume that it is the attributes of individual actors—whether they are friendly or unfriendly, smart or dumb, etc—that matter. Social network theory produces an alternate view, where the attributes of individuals are less important than their relationships and ties with other actors within the network. (Wikipedia, 2005)

A person with more connections to others, in a variety of social worlds, has access to more information and opportunity than a person who only interacts with a small group of others. It seems obvious that these linkages take time to develop, and that the removal of persons from their previously enjoyed networks creates a disruption in the amount of information or opportunities that they can access (until new linkages can be developed). Social networks are both stable and transient over time (Bronfenbrenner, 1990; Larner, 1990). Social network analysis is easily embraced by social workers because it is based on the assumption of the importance of relationships, on an understanding that the

network's structural environment provides opportunities for, or constraints on, individual actions (Wasserman & Faust, 1994) and that a change in even one relationship creates different options for behavior and support.

Exchange theory refines this approach by including the appraisal of *value* of certain relationships or information exchanged, in terms of perceived costs and benefits to the actor. It emphasizes the role of choice by actors, who are not passive recipients of the exchanges occurring in social networks. Rooted in part in behavioral psychology (University of Akron, n.d.), this theory clarifies that different recipients will appraise and act on the same information or the same type of relationship differently, based on the complex combination of rewards (or punishments) expected by the actor when participating in the exchange. It asserts that people are goal-oriented, rational, and seek to calculate the best possible means to attain the desirable outcomes (benefits) with a minimal amount of cost, all of which are appraised subjectively given one's current situation. Homans (1961) and others elaborated that the resulting power differences between people that result from exchanges are important costs or benefits to consider (University of Akron, n.d.).

These concepts are seen in Brett's (2004) description of the journey that parents of disabled children make toward accepting support in their caregiver roles. She proposes there is an expectation in western society that parents, especially mothers, will meet the needs of their children within the home. Additionally, she describes the differing appraisal of the child by such parents as compared to general society, which tends to frame the disabled child as a burden

or tragedy. According to Brett, parents of disabled children often do not appraise their children in this negative way, so to accept or ask for support services that are grounded in that perspective seems an admission of failure or a form of loss (Brett, 2004). She further emphasized that professional service providers need to recognize the individual family's appraisal of their situation and of what the receipt of support will mean to them. "Knowledge of this complex process makes clear the importance of questioning why support may be refused by parents or why parents may not seek support" (Brett, 2004, p. 18). In describing why she undertook her research, Brett cited few studies of parents specifically being asked about their experiences of support and how their appraisal of the meaning of support services affected their choices. This perspective, guided by social network and exchange theories, is one of several that guided the approaches of the current study.

Exchange and social network theories help explain individual variations in behavior while recognizing the impact of the overarching social context. The uniqueness yet also universality of human experience may be further described using humanist and developmental theories, presented next.

### ***Humanist Theory, Developmental Theory, and Plasticity***

As mentioned, an explosion of scientific research occurred in the late 19<sup>th</sup> Century and throughout the 20<sup>th</sup> Century. This included exploration into the biological and interactive developmental processes of child development, involving experts from both medicine and education. Examples of these are Erikson (1963), Gesell (1925), Kohlberg (1984), and Piaget (1962), to name

some of the more influential. Thousands, possibly millions, of American parents have been influenced by Dr. Spock, Dr. Brazelton, and Dr. Leach in determining appropriate actions toward their children. The common theory behind all of these influences is that children, by nature, progress sequentially through predictable developmental stages. A subtle assumption that also emerged from this scientific focus was the professionalization of child specialists, with a level of authority over parents regarding child welfare (Bowe, 1995a).

According to these theories, the role of these experts is to identify at which stage(s) of development (i.e. cognitive, physical, and moral) the child is currently; then to provide an environment that reinforces the accomplishments of that stage toward preparation for a natural step into the next stage. Doing nothing, or not providing the necessary supports, results in harm and individuals who do not contribute to society (Bowe, 1995a). These theories pointed out the futility of expecting individuals to perform at higher developmental levels than their current levels allowed; but also, that by providing the right support, an adult could facilitate the movement of any child into a more advanced developmental level (Dunst, 1992; Piaget, 1962; Piaget & Inhelder, 1969). Striving toward a more advanced stage is seen as the natural goal for all people, and its accomplishment as a benefit to society. The fields of early intervention and early childhood special education exist because of developmental theory's contribution that childhood deficiencies can be corrected by the proper environmental actions (Bowe, 1995a). This is the concept of *plasticity* (Hauser-Cram et al., 2000; Kagan & Neuman, 2000; Ysseldyke, Algozzine, & Thurlow, 1992). However, whom the

best persons are to actually do this—parents, medical professionals, early education specialists—has remained a topic of debate.

Within developmental theory we see an overlap with humanistic and existential theory, concerned with the meaning of life and the attainment of the full potential of each individual. Maslow's hierarchy of needs model (1954) asserted a natural order in the human seeking of satisfactions, beginning with the most basic of safety and survival and continuing, for all persons, toward self-actualization. Perhaps because of the suffering endured and observed during the two world wars, the focus on humankind's ability to rise above suffering, to make meaning out of it, and our obligations to challenge unnecessary suffering were strengthened during the middle and latter parts of the 1900s. Americans have embraced humanistic philosophy and theory because of the strongly shared value for autonomy, and for the protection of individual liberties (Loewenberg, Dolgoff, & Harrington, 2000). The value of life and of each individual exists for Americans above any economic measure, and is strengthened by tightly held Judeo-Christian teachings.

These approaches celebrate the worth, dignity and potential of all human beings, and are thus related to the strengths perspective, highly valued in social work. It is presented next as a guiding theory of both early intervention and early childhood special education practice and research.

### ***The Strengths Perspective***

The strengths perspective is closely identified with humanistic approaches. As stated by Early and GlenMaye (2000), this perspective is in line

with humanist approaches, asserting that humans have the capacity for growth and change. The authors further elaborated:

Individuals and families all have many capabilities, abilities, and strengths. People who seek help with problems are more than the problem. Each person has a range of experiences, characteristics, and roles, which contribute to who the person is (Saleebey, 1997a; Weick, Rapp, Sullivan, & Kisthardt, 1989). Families have traditions, rituals, and the combined capabilities of family members. Families also share the strengths of other systems in which they are embedded, such as extended family and neighborhood. From an empowerment perspective this means that families already are competent or they have the capacity to become competent. (Dunst, Trivette, & Deal, 1994, electronic version, Underlying Assumptions section, para. 2)

This description of the strengths perspective is particularly relevant to this study because it includes the strengths of families and communities, and recognizes family and community capabilities, competence, and resilience (versus deficiencies), when addressing social needs.

Saleeby (1996) reminded practitioners and researchers of the importance of the language used by agents of social services. He asserted that the system--the bureaucracies and organizations of helping--is often diametrically opposed to a strengths orientation. In both formal and informal venues and structures, policies, and programs, the preferred language replaces the clients' own lexicon with the vocabulary of problem

and disease (Goldstein, 1990; Saleebey, 1992). Finally, the professional language and the metaphorical devices social workers use to understand and help sometimes subvert the possibility of understanding clients in the light of their capacities. Pursuing a practice based on the ideas of resilience, rebound, possibility, and transformation is difficult because, oddly enough, it is not natural to the world of helping and service. (Saleeby, 1996, electronic version, Elements of the Strengths Perspective section, para. 3)

It is important, then, to examine professional activities, including research, to guard against pathologizing families and communities, either in language or approach.

### ***Stress Theory***

Stress theory is similar to ecological perspectives because it emphasizes environmental impacts, what happens to people, as major contributors to distress and social *problems*. It is similar to strengths perspectives in that it steers away from the view of individual failings as the cause of social problems, and normalizes human reactions to abnormal situations. Stress theory values the abilities of people under stress to recover (vs. hopelessness or dependence on experts). It recognizes that, ultimately, management of stressors and of reactions to stress can only be successfully performed by those experiencing the stress. Thus it empowers families in the healing process, and frames the role of professionals as guides or teachers.

One model widely used to represent stress theory is the classic ABCX model, originally proposed by Hill (1949). In this model, A represents the stressor event, B represents the family's internal crisis-meeting resources, C represents the family's definition of the stressor, and X is the resultant prevention or precipitation of crisis based on the interaction of A, B and C (Gallagher & Bristol, 1989). McCubbin and Patterson (1981) expanded this model by proposing a Double ABCX, or *Family Adjustment and Adaptation Response Model (FAAR)*, which is described as adding (aA), the pile-up of other stresses which make adaptation more difficult, (bB) which addresses the social resources available in addition to psychological ones, and (BC) (sic) which addresses the learned coping strategies (Gallagher & Bristol, 1989). These later factors are those than can be directly impacted by effective early childhood services.

Numerous researchers have documented the specific stress experienced by caregivers of disabled or special needs family members (e.g., Bailey & Simeonsson, 1986; Gallagher & Bristol, 1989; Lessenberry & Rehfeldt, 2004; Saunders, 1999; Singer et al., 1993). Specifically with regard to evaluating the stress levels of parents of disabled children, Lessenberry and Rehfeldt (2004) propose four domains that comprise the concept of stress: (a) the stressor, (b) strain (the physical and emotional symptoms experienced in conjunction with a stressful event), (c) coping resources, to include social support networks, and (d) coping strategies. This model further reinforces the ecological context of providing services by identifying community-based points of intervention that can have direct beneficial effects on families. It also reiterates the positive impact on

children of strengthening families' own coping abilities, versus viewing families as passive recipients of services.

In addition to its emphasis on availability of social support networks, stress theory is important to the development of the study described in later chapters for another reason as well. The recognition of the role of *appraisal*, or the perceived meaning, of an event or situation by those involved is critical to developing effective responses. This component helps to explain why seemingly useful resources are often not used by those for whom they are intended. For this reason, it became important to the researcher to ask respondents about their perceptions of what their experiences mean and what they perceive to be useful resources in response. Dunst, Trivette, and Deal (1988), focused on these aspects in their research using the family empowerment model. They emphasized the importance of eliciting and supporting objectives determined by families as decision-makers (Krauss, 2000). Families under stress are not necessarily incapable of making decisions or taking action, but may need support to maintain these functions under times of stress.

#### ***Role Strain***

Related to the previous discussion, there is a body of theory that specifically addresses what happens to people when conflicting or heavy demands for coping exceed the ability to meet the demands positively. Grant-Vallone and Donaldson (2001) outlined the research documenting the effects of work-family conflicts using general stress models and role theory. They reported outcomes documented in this body of research that included higher stress,

increased depression, physical ailments, lower life satisfaction, lower quality of family life, lower energy levels, and lower life satisfaction.

Bourg and Segal (1999) outline two recent societal trends that contribute to increased competition for the energy and attention of military members. These are (a) a dramatic rise in the numbers of wives and mothers in the general labor force, taking them away from full-time home management, and (b) changing cultural norms which call for more active involvement of husbands and fathers in family functions. These have increased the potential for conflict between the two *greedy institutions* of the military and the family (Bourg & Segal, 1999, citing the work of Coser, 1974 and of Segal, 1986). A body of literature about how individuals and specifically military members manage competing demands of work and family has emerged in the last two decades (e.g., Greenhaus & Beutell, 1985; Kanter, 1977; Marks, 1977; Segal & Harris, 1993). These studies and others are relevant to the strains experienced by military parents who must (a) juggle care giving demands related to special needs (on top of the already heavy responsibilities of parenting children in general), (b) build full-time careers, (c) respond to three and four-generational care giving demands, (d) accommodate the rapid geographic mobility of military families, and (e) function in positions that are often not limited to established working hours or schedules.

Role strain theory is evident in retention concerns for active duty service members. Changing demographics in the general labor force and specifically the military have brought increased focus on the need to support parents, particularly mothers, in managing their demanding roles. A recent report released by the

Defense Advisory Committee on Women in the Services (DACOWITS) provides data that women service members departed military service in 2004 at higher rates than their male counterparts (DACOWITS, 2005). This occurred in all ranks except the very highest, ranks in which persons are least likely to have child care responsibilities because of the ages they represent.

The Air Force Times cited the DACOWITS report and claimed "balancing work with home life is a major issue across all ranks and all services . . . 71% overall and 83% of female junior officers said problems balancing work and home life were primary considerations in staying or leaving" (April 25, 2005, p. 26). This article stated that even though officers with children were more likely to report an intention to stay than those without children (of both genders), those with children actually did separate at a higher rate in 2004 than those without children, with female officers separating at the highest rate. It was acknowledged in this article that the same pattern occurs in the private sector, but that the difference is civilian employers are more flexible than the military in granting time off, allowing part-time work, and giving families more say about moving (*ibid*). Women in the private work force do leave jobs during critical periods of childcare demands, but are much more easily reintegrated into the work force due to this flexibility. Once separated from the military women are not likely to return, representing a huge loss of investment, skills and experience. The DACOWITS report recommended consideration within the military of alternatives to retain women, such as career tracks that are less deployment intensive, and leaves of absence or sabbaticals for special child-rearing situations (AF Times, April 25, 2005).

This call to the military to adapt its family support structures to the families of today is consistent with Bourg and Segal's work (1999). Their stated main hypothesis was that in recognizing the legitimacy of family demands and in providing a framework wherein both sets of demands could be met, the military could create an environment in which service members maintain a high commitment to both the military and family institutions. Just how to do that is as yet unresolved, as seen in the recent DACOWITS report (2004). According to Crawley (2005), "the challenge of balancing family and work is the main reason people leave the military" (p. 31). In reviewing the DACOWITS report, he stated the inflexibility of workload and schedule was the factor most frequently cited by those intending to leave the military (Crawley, 2005).

It is with this theoretical underpinning about stress, role strain, and their combined impact on military retention that the current study seeks to expand an understanding of these phenomena in special needs families. Specifically, the researcher attempted to identify the perception of special needs families regarding the likelihood of leaving military service due to the demands of rearing a special needs child. This study sought to examine what other factors, such as rank or severity of need, are highly associated with the perceived likelihood of leaving or other perceived impact to the military career. Additionally, from these theoretical perspectives, the study seeks to elicit the perceptions of these families with regard to the adequacy and responsiveness of available support resources with regard to their particular needs.

At this point attention will now shift from a discussion of underpinning theories, to a description of the overarching service paradigm within which families must obtain services. This step is necessary toward identifying the research questions that guided this study.

### **Emerging Changes in the Service Paradigm**

Specialized services for families with young special needs children are provided under the auspices of early intervention and early childhood special education. These fields, while separate in some operational details, are described as a joint system here because they share (a) a common historical background, (b) some common aspects of infrastructure, (c) social theories which explain them, and (d) some emerging changes in the accepted paradigm for service delivery. These are described in the following sections: (a) focus on families, to include further subsections described next, (b) early identification using multiple perspectives, (c) natural environments, (d) service integration and coordination, and (e) building capacity. The primary emphasis in the extensive literature of both early intervention and early childhood special education is the increased emphasis on focusing services on families, described next. This elaboration of what the service system is intended to be is important to the task of evaluating how effective it is for the subgroup identified for this study, military families.

### ***Focus on Families***

This section will describe aspects of the new paradigm with regard to a focus on families, instead of individual children. It is presented in these

subsections: (a) family functioning, (b) families as members of the team approach, (c) empowerment of family decision-making, and (d) sensitivity to family diversity, to include the role of culture, differing concepts of community across families and cultures, and the military as a specific community and culture for consideration.

The evolution of the early intervention/early childhood special education field as a new science has experienced a paradigm shift in the last 30 years. Originally conceptualized as a service that professionals *do to* individual children to remediate deficits in their development (perhaps as a temporary parent substitute), both early intervention and early childhood special education now generally incorporate a broader view of the purposes, agents and targets of professional efforts. Mahoney and Filer (1996) provided a clear description of this evolution from professionally-driven, center-based models to family-centered home-based (or other natural environments) models. Rather than a focus on correcting the deficits of the family, the emphasis has evolved to supporting the families who rear disabled children. An additional shift has occurred in the process of research and evaluation, inviting the perceptions and desires of the families themselves (Able-Boone, Sandall, Loughry, & Frederick, 1990; Harrison, Dannhardt, & Roush, 1996). The goal now is for families to become full partners in the early intervention/early childhood special education process (Mahoney & Filer, 1996).

Research that emerged in the mid 1980s (Bailey & Simeonsson, 1986) challenged clinicians to look beyond changing the child to understanding and

serving the needs of families with disabled children. Reasons included the recognition of the tremendous impact of the family on each child's development, and of the tremendous impact of the presence of a disabled child on family functioning (Bailey & Simeonsson, 1986). The reauthorization of the EHA in 1986 (PL 99-457) "extended the initial mandate of PL 94-142 for parental consent and involvement in educational decision making to define a critical role for families in the development and education of their very young children" (Harrison et al., 1996, p. 203). It was at this time that the assessment and inclusion of *family* strengths and needs became mandated in the required Individualized Family Service Plan (IFSP), as well as "a statement of the major outcomes of early intervention for the family" (Summers & Turnbull, 1990, electronic version, para. 3). Crnic and Stormshak (1997) stated that "the family is the primary developmental context for young children, regardless of their risk or disability status, and family functioning is a critical determinant of eventual child competence" (p. 209).

As predicted by Bailey (2000), ongoing research focuses less on the child's IQ or developmental quotient as desirable child-based outcomes, but rather on which services provide the needed support to families raising these children (e.g., Guralnick, 1997a; Malone et al., 2000; Wolery & Bailey, 2002). Goals for both early intervention and early childhood special education have thus shifted from raising developmental quotient scores, similar to IQ scores for older children, to a more ecologically-based (Bronfenbrenner, 1979; Black, 1991), or systems approach, focusing on the interactions of the child with family and with

natural environments, such as day care. Communication, and adaptive behavior are listed as 2 of the 5 primary developmental areas for interventive focus in the Part C legislation, emphasizing the desire for each child to function maximally in their own social context, vs. merely scoring higher on individualized cognitive or physical performance measures (Hanson & Bruder, 2001). Functional and social competence (of both child and family) has replaced the acquisition of developmental skills as the primary goals of early intervention (Blackman, 2002; Crnic & Stormshak, 1997). Singer and Powers (1993) promoted a more holistic, family and community-centered orientation, and advocated for efforts that "minimize suffering and maximize future adaptability" (p. 7).

### ***Family Functioning***

Family functioning has been linked to the ability to rear all children optimally, as well as to job performance and to community well being. Specifically within military occupations where the safety of others is frequently at risk, the strength of family functioning is undeniably important and has served as the justification for the roles played by first sergeants and social workers. Family functioning, it is argued, supports other societal priorities, such as taxpayer savings for special education, and the use of the least restrictive environments in lieu of institutionalization (Bricker & Kaminski, 1986). Dokecki and Heflinger (1989) explained that the stated intent for society in Part H of PL 99-457 was to reduce educational costs, prevent institutionalization, and maximize citizens' capacity for independent living. All of this was to be accomplished via

strengthening families through the various levels of the intervention system (Dokecki & Heflinger, 1989).

While direct remedial clinical services provided to children continue to be valuable, the fields of early intervention and early childhood special education are increasingly focused on caring for the caregivers. Weatherford (1986) outlined goals for early intervention (and on which its evaluative research might focus) in relation to strengthening family functioning: (a) facilitate positive interactions between handicapped children and their parents, (b) teach parents how to cope with the stress of rearing a handicapped child, (c) teach parents how to be effective teachers for their children, (d) improve conditions for the siblings of handicapped children served in the programs, and (e) provide respite for parents of handicapped children (Weatherford, 1986). All of these contribute directly to family functioning.

#### ***Families as Members of the Team Approach***

All currently supported models of service emphasize the importance of teamwork, and that no one provider can provide family-centered care as well as an integrated team of professionals. (Given the extensive needs of many of these families, not many providers even want to work solo any more!). Also emphasized is the inclusion of families and/or caregivers as core members of the interdisciplinary team, not just recipients of services. The importance here is on the establishment and maintenance of networks of professionals and community stakeholders, including parents, who share ideas, responsibility, resources and commitment to support these families.

The importance of the family role in a multidisciplinary team has been supported in research that validates the accuracy of caregivers' own assessments of the child's needs (American Academy of Pediatrics, 2001; Garshelis & McConnell, 1993; Hendrickson, Baldwin, & Allred, 2000). Additionally, efforts that are directed at admirable goals but not those prioritized by the family are not likely to succeed. Thus, asking each family what they desire from early intervention is now recognized as the starting point for both services and effectiveness research.

### ***Empowerment of Family Decision-Making***

Embedded within family functioning, and identified as a core goal of early intervention programs, is the professional support of the family in making decisions regarding their children (Dunst, Snyder, & Mankinen, 1989; Duwa, Wells, & LaLinde, 1993; Hurth & Goff, 2002). This emphasis has occurred as a paradigm shift in the last three decades, away from clinician-driven approaches to a more family-driven method (Guralnick, 1997a; Krauss, 1997; Mahoney & Filer, 1996; Neisworth & Bagnato, 1996). Providing the necessary information for decision making, in a manner sensitive to the abilities and desires of the family, is now seen as a primary role for professional teams serving these families (Mahoney & Filer, 1996; Singer & Powers, 1993a).

The need for information is cited consistently as a top priority for families (Able-Boone et al., 1990; Duwa et al., 1993; Gowen, Christy, & Sparling, 1993; Summers & Turnbull, 1990; Ziegler, 1989). This is consistent with the perspective that caregivers are able and desire to take active roles as decision makers in

early intervention services. As a parent of a disabled child stated, "Making decisions is responsibility: making effective decisions is power" (Ziegler, 1989, p. 85). Viewing families as valued members of the service team is the best way to remove them from the dependent role, and to reduce the fragmentation of services inherent in the "specialist-driven care system" (Kohrman & Diamond, 1986, p. 86). Having an established seat at the table ensures that families receive information, are able to provide information, and are empowered as decision makers. This is the intent of the provisions and revisions of the EHA and IDEA. "The primary safeguard provided for in Part C is the clear acknowledgement of the family's role as a primary decision-maker in developing an IFSP [Individualized Family Service Plan]" (Hurth & Goff, 2002, p. 2).

Singer and Powers (1993) discussed these new principles of support in the context of building resilience, emphasizing that "all families have strengths" and the "capacity to change and grow when the proper facilitating conditions exist." (p. 5). They described the role of practitioners, to

identify resources and match them to family needs as *the family perceives them* rather than trying to fit families into rigid programs . . . the ultimate power of decision making resides with the family. A successful partnership in this model results in family members becoming more efficacious at attaining their goals and more resilient in the face of future stressors.

(Singer & Powers, 1993, p. 5, italics in original)

This approach reflects the systems perspective of *social competence* as the goal for both the child within the family, and for the family within the social environment.

Rather than *managing* the child's care (making decisions and directing families in what to do), a more productive approach now involves sharing information and options, discussing alternative risks and benefits of possible choices, and supporting the values and decision-making capabilities of the family. Nickel and Gerlach (2001) provided an excellent discussion of risk communication and health care decision-making, as well as a clear list of "what families want from providers" (p. 74). They also examined other ways to support parents in their communication abilities with providers (Nickel & Gerlach, 2001), a skill that will serve mobile families well.

### ***Sensitivity to Family Diversity***

It is important, however, to not homogenize families and their respective levels of need for information. Gowen, Christy, and Sparling (1993) emphasized the need to consider different gender-based and education-level based needs for information. From a family-driven perspective, it is also essential to remember that different families have different levels of interest and the ability to participate in team functions. This section addresses this need to consider the diversity of families encountered by early intervention and early childhood special education professionals.

Duwa and her colleagues (1993) provided an insightful guide to creating family-centered programs in which the voices of parents with special needs

children are heard. The section on *Respect for family diversity* begins with this quote from a parent: "You can't even begin to imagine what it is like in our home. We have to deal with a lot more than Courtney's problems. If we can't get the other things done, we can't take care of her"(p. 99). The authors continue:

Everyone has a set of unique strengths and coping mechanisms based upon generations of family values (Roberts, 1990). . . . Family sensitivity is part of assuring respect for the families. It is impossible for professionals to understand all the influences that govern families' behavior and decisions concerning their child (Kaufmann & McGonigel, 1991). We have learned through our work that it is unfair to families to ask or allow professionals to make assumptions about families based upon small pieces of information. (Duwa et al., 1993, p.99)

This need for sensitivity to the uniqueness of the family must begin with the identification of a special need. Frequently, it is parents who first suspect that something is *wrong* or different with their children. Hendrickson, Baldwin, and Allred (2000) used qualitative research methods to investigate parents' experiences in seeking help for their children, specifically focused on mothers' perceptions of what prevented families from getting help earlier for their special needs children. In their sample, all but one mother reported their concerns to their primary health care providers. The one who did not reportedly did not do so because she felt the pediatrician had not worked with her previously to find help regarding an older child. Of those who did report developmental concerns to their pediatricians, the authors reported "In every case, the mothers reported that the

physician did not take their concerns seriously, and the parents felt that they had to seek advice elsewhere" (Hendrickson et al., 2000, p. 9). The authors also stated that "All of the mothers reported that their interactions with their medical care providers was a barrier(!) to finding appropriate services" (emphasis added, p. 9). The intent here is not to target physicians, but to invite all professionals to examine whether their communications with families convey respect for their knowledge and abilities regarding their children. Attempts to reassure or to steer parents away from complaints may not be perceived as sensitive to their needs and may block future needed communication.

Conversely, when the physician or other professional initially identifies a chronic or severe disability, the way it is presented to the family requires utmost sensitivity to the uniqueness of the family. Ziegler (1989) described the research of a French physician, Dr. Zucman, who claimed "that families suffered an added handicap, one brought on, at least in part, by what she refers to as the 'violence of disclosure'" (p. 86). Ziegler further studied the professional-parental interactions surrounding the communication of the disability to families as "unduly pessimistic" and cited an observation (p. 87) made by a father in Turnbull et al.'s chapter of Dokecki and Zaner's book of 1987:

When normal children are born, the doctors do not recount for parents all of the problems that could happen to their child, like drug involvement, flunking out of college, sexual promiscuity, or teenage suicide; however, when a child with Down syndrome is born, the doctors only point out the negative. (p. 123-124)

Ziegler continued, "Such negative attitudes and behavior on the part of the primary caregivers can have devastating effects on crucial decisions that must be made by the parents" (p. 87). This is echoed in parental expectations of professionals identified by Able-Boone et al, (1990), who reported the parental desire for "accurate information, positive reactions, I don't want anyone telling me there are ceilings or limits" (p. 106). Thus, great sensitivity is required in assessing parents' readiness and/or diversity of expectations in first identifying and examining the child's abilities and needs.

Furthermore, sensitivity must be extended to the families who choose not to participate actively in the team approach on an ongoing basis, or who choose alternatives not favored by the team's professionals. It is very difficult for some professionals to refrain from imposing their values or beliefs when there is disagreement regarding what is best for the child. Sensitivity to the family's prerogative to make their own decisions, as is required under current service models, presents some ethical challenges, at times, for multidisciplinary teams.

Sensitivity is also a requirement of current intervention paradigms with regard to the wide range of emotions experienced by caregivers. Summers and Turnbull asked us "to consider the possible unintended consequences of casual comments or program expectations...[as well as] the importance of conducting all interactions with families in an unhurried atmosphere in order to convey the sense that family concerns and needs are important to practitioners" (Summers & Turnbull, 1990, electronic version, Results section, Early Intervention Program Principles, para. 2). These authors cited family preferences for informal

approaches and open-ended conversations, versus structured interviews, and a willingness of professionals to invest time in developing rapport (Summers & Turnbull, 1990.)

***Role of culture.*** As in all areas of social work practice, the striving for cultural competence by the worker in relation to her clients is an ethical imperative. Within the early intervention and early childhood special education disciplines, inclusion of the child's and family's culture is integral to effective service delivery. Extensive research exists documenting the futility of viewing children separately from the cultures in which their families rear them (e.g., Brookins, 1993; Garbarino & Ganzel, 2000; Garcia Coll & Magnuson, 2000). This aspect of sensitivity to family diversity has become a primary component of the current service paradigm. The current understanding of culture demands that professionals look beyond visible indicators of culture (such as ethnicity). Service providers need to ask families about more latent aspects of culture, such as where this family chooses to obtain support, in order to tailor a culturally appropriate service plan.

***Differing concepts of community.*** Different cultures define community differently, and an evolutionary change has taken place regarding where most Americans now look for community or social support (Bronheim & Striffler, 1999; Magrab, 1999). In the early years of American history, families looked to their kin and to the church for assistance. Later, employers and local communities served these support functions. As society became more complex, using systems theory, wider circles of states and service systems became the source of social

relief. The expansion of the federal government into the maintenance of social welfare in the 20<sup>th</sup> Century reflected the social norms of equality and distributive justice that were highly popular in the 1950s, 60s, and 70s. Yet this inclusiveness suffered the financial strains of its obligations, with growing populations and operating costs. Combined with global economic shifts of the 1980s and 90s, and frustration with the unresponsiveness of massive social programs, the federal government is not always seen as either able or appropriate to manage many forms of social support. A growing mistrust in big government, fueled by concerns for the solvency of the social security program, reports of the scandal of the week, and a resistance to increased taxes, have helped to shift some of the expectation for social programs to lower levels of government and to the private sector (Karger & Stoesz, 2002; Popple & Leighninger, 1998). It is likely this will continue in coming years.

Related to this is a changing definition of community. Whereas community, with its connotation for belonging and involvement, was formerly considered family and a geographically situated entity, Americans now often think of community as a shared sense of solidarity and significance (Magrab, 1999). This psychologically situated community increasingly involves informal support networks, professional associations or groups that form around leisure interests. People may be more likely today to seek support from strangers with a common need than from family or neighbors (Bronheim & Striffler, 1999). Connections may form across many miles through expanding use of the internet. These groups have a powerful impact on decision-making against delivery

systems that are based on location, such as state-based determinations for levels of care.

Another aspect related to cultural conceptions of community and of family diversity is the family's preferred source of support, which will probably vary over the life stages of the family. Many families expect to receive support from a combination of professional and non-professional sources. Some families seek expert or professional resources only; some prefer to locate their own resources via the internet or libraries; and others desire a connectedness to other families who experience similar situations. During assessment and service planning, professionals serve a vital role by offering resources outside of their own scope. Along with recognition of the importance and strength of families in the current delivery paradigm, is the value placed on nonprofessional knowledge and social support. "Parent-to-Parent" programs and self-help or support groups (Santelli, Turnbull, Lerner, & Marquis, 1993; Singer & Powers, 1993) frequently provide the needed information, the opportunities for divergent viewpoints to be explored, and the continuity in the community that families need. Professionals have a role in supporting the growth of these associations and in linking families to this vital source of emotional support that they themselves are unable to provide.

***Military as a culture and a community.*** Rubinstein (2001) cites Hays's (1994) definition of *culture*: "systems of meaning . . . including not only the beliefs and values of social groups, but also their language, forms of knowledge and common sense, as well as the material products, interactional practices, rituals, and ways of life established by these" (pp. 1 – 2 of Rubinstein). Brookins (1993)

describes culture as "the sum total of mores, traditions, and beliefs of how we function, and encompasses . . . the man-made part of the human environment including not only artifacts but also laws, myths, and special ways of thinking about the social environment" (p. 1056). Using either of these ways of understanding culture, it is easy to argue that the military has its own culture. Long-term members of the military and their immediate families become acculturated over time into this military culture, integrating it with aspects of their other cultures related to ethnicities or locations of origin. Service delivery professionals must recognize the entirety of cultural influences on military families in order to effectively serve them.

Additionally, the military is its own community in that its members share a sense of belonging and loyalty to each other, regardless of other interpersonal factors. This military community is superimposed over concepts of community that are based on geographic location. The military community is seen in networks of support that are provided formally by the Department of Defense, as well as in informal support networks that develop spontaneously among military families, even across thousands of miles. Both reflect this sense of mutual responsibility for the common welfare of all military community members.

**Summary.** As traced in the preceding discussions, any early childhood service paradigm must be family based, culturally appropriate, and community situated. Services delivered to military families must be sensitive to military family culture and concepts of community in order to be effective. Another aspect emphasized in the literature is that services must be multi-disciplinary with a

focus on identifying needs or concerns as early as possible. This is elaborated next.

### ***Early Identification Using Multiple Perspectives***

This section further elaborates essential elements of a service delivery paradigm developed in the early intervention and early childhood special education literature. Given what we have learned about the critical windows of opportunity for developmental intervention and about the role of the community in supporting child rearing, proactive community efforts toward early identification have become more prevalent. No longer can we depend on the physician to identify all children and families with needs amenable to early intervention. Widespread screening programs have expanded into daycare and community centers, health departments, and into related service centers such as Services to Women, Infants, and Children (WIC) offices, substance-abuse prevention, and domestic-violence prevention activities. IDEA now requires early intervention programs "to conduct comprehensive and coordinated child find activities" (Harbin et al., 2000, p. 389) to identify children who might benefit from services as early as possible. The early detection of developmental delays or family needs from a variety of sources is a core part of current service delivery models.

Once developmental concerns are suspected, a variety of measures is needed for further assessment and service planning. Standardized assessment batteries, behavioral observations, family interviews, and multiple methods are preferred to capture the scope of interventions that may be possible and desirable. Black (1991) discussed these *multiplicative indexes* as a major

challenge, yet essential to addressing "two significant risks: selecting children who are not at risk and do not require early intervention and missing children who are at risk and should receive early intervention" (p. 53).

Using a variety of types of assessment tools and a multidisciplinary team of experts approach is especially supportive of mobile military families. Each state is authorized by the federal government to establish its own criteria for eligibility to publicly-provided early intervention services, and accordingly, each state uses different criteria in these determinations. Benn (1993) clarified that the federal regulations suggest that psychometric criteria . . . and/or informed clinical opinion can be used as the basis for identifying children with developmental delays. Although no single procedure is permitted to be used as the sole criterion for determining a child's eligibility, states may consider the use of two standardized tests to suffice, rather than two different assessment approaches. (p. 20)

Therefore, as might be expected, states do use a vast array of different approaches for criteria that may be included in access eligibility determinations: (a) divergent levels of difference measured in one or more standard deviations from the mean on standardized measures, (b) documentation of informed clinical opinion, and (c) divergence from percentiles on developmental milestones, and other types of measures. Documentation of environmental risks can be even more complicated. Again, multiple measures and factors need consideration (Benn, 1993). Families who move frequently and encounter these differing

standards for services require documentation that includes a variety of indicators of need in order to access services quickly after relocation.

### ***Natural Environments***

Another aspect of currently favored service delivery models involves the location of planned services. Early intervention efforts are increasingly provided in natural environments (as opposed to the clinician's office), and include individual caregivers who were not traditionally included (Hanson & Bruder, 2001). Both early intervention and early childhood special education are now occurring in such places as grandparents' homes or with babysitters or daycare providers. Shelden and Rush (2001) documented numerous benefits of this approach, including more generalization of learned skills, better reception of services by parents, and more cost effectiveness.

Decentralizing services back into local communities (away from distant medical centers) supports the development of family confidence and sense of normalcy. Duwa and her associates (1993) stated that many families used their own levels of participation in the community and acceptance by the community to measure the success of their lives. Being able to receive services in locations in which they would normally interact with others confirms the value of the family and their normal routines, and protects them from the stressful experience of venturing into foreign territory. "Self-image and family security will be enhanced by inclusion in a service delivery system that is similar to that of other families living in their community" (Duwa et al., 1993, p. 97). They cited research by Diehl, Moffitt, and Wade (1991) in which

families of children with special health care needs tended to feel more secure and accepted when they were receiving community-based services that acknowledged that their child is a child first, with many needs not unlike those of others the same age. (Diehl, Moffitt, & Wade, 1991, as cited in Duwa et al., 1993, p. 97)

#### ***Service Integration and Coordination***

After focusing on families, promoting early identification, and providing services in natural environments, a fourth feature required of teams and services in the new paradigm is that they must be both integrated and coordinated. After a brief discussion, next, this feature is described further in subsections of *fragmentation and case management* as important considerations.

As the profession developed, services evolved and proliferated across disciplines and funding streams. The result has been increasing complexity in accessing services, as well as duplication of some services and the omission of others in many locations. Roberts, Akers and Behl (1996) distinguished between *service integration*, which is a methodical effort toward efficiency and effectiveness of delivery systems with the goal of improving outcomes for families, and *service coordination*, which they described as "bringing together previously uncoordinated services at the family level. Effective service coordination for families is predicated on the foundation of an integrated service system at the community, state, and federal levels" (Roberts, Akers, & Behl, 1996, p. 281).

### ***Fragmentation***

Many believe that more effort needs to be directed to streamlining the complexities of the system (service integration) to reduce the demand for, and difficulties of, service coordination with each specific family. Salisbury, Crawford, Marlowe, and Husband (2003) discussed this issue as they described an innovative project to address the apparent fragmentation of services at the broadest levels. They cited numerous recent research studies that found that

child and family services are often fragmented, compete for limited funds, provide redundant or competing services, and lack effective communication channels within and across agencies . . . most efforts have sought to improve cooperation among agencies rather than address structural, legal, attitudinal, and fiscal constraints that more substantively affect service coordination and the integration of services at the community level.

Studies suggest that interagency agreements and alliances, blended funding, consolidation of programs, coordinated policies and personnel development, co-location of services, and flexible scheduling can influence the nature and extent of services integration within and across organizations. (Salisbury et al., 2003, p. 60)

These authors recognized the IFSP as a “useful cross-agency planning tool” but outlined its shortcomings in integrating vs. coordinating services, emphasizing “the need for alternative strategies at the local level” (p. 60). Their article

discussed a model plan for doing so to alleviate the hardships faced by families who pay the greatest price for the fragmentation of service bureaucracies.

As good intentioned as service providers are known to be, administrative structures and reimbursement schedules provide little support for the time and travel needed to coordinate the necessary linkages for deserving families. Many service providers are faced with expectations for productivity that are based in clinic or center counts, which leave little room (and no money) for cross-professional collaboration--particularly between civilian and military service systems. Those who do take their own time to meet and understand other service systems have little opportunity to design the ideal network, and are faced instead with patching together something that works—for now. Staff turnover and constant policy and budgetary changes make both formal and informal agreements difficult to actually implement.

The literature consistently identified the challenges of coordinating services at the family and local levels within a context of competing and complicated policies and practices at the largest levels, such as federal and state systems. Guralnick (2001) called for well-known and easily located points of entry and for web-based information transmission systems linked to a central database (with appropriate protections for confidentiality) as ways to strengthen both integration and coordination efforts. Current service models recognize interdisciplinary collaboration as essential to the success of families (Malone et al., 2000). This needed collaboration can be seen as extending beyond clinical practices that involve families, to the community infrastructure and to state and

federal policies that undergird professional efforts. This role or function may be described as case coordination, or case management.

### ***Case Management***

Emphasis in both the early intervention literature and in military family support venues is increasingly placed on the need for integrative and collaborative efforts among separate service providers. Opposed to requiring families to manage a wide variety of service locations, policies and program goals on their own, the current model of effective service delivery requires professionals to initiate and maintain linkages across widely divergent sources of family aid (Roberts, Innocenti, & Goetze, 1999; Spiker, Hebbeler, Wagner, Cameto, & McKenna, 2000; see also National Military Family Association and Military Family Resource Center websites). *Stove-piped*, encapsulated, or territorial services are potentially conflictual with each other in their goals and methods, and serve only to further frustrate and disempower families. Particularly in the fields of early intervention and early childhood special education, in which professionals from social work, education, medicine and other health-care specialties all provide needed assistance, professionally initiated service integration, collaboration and coordination has been shown to be a requirement for enhanced family functioning and beneficial developmental outcomes (Krauss et al., 2001; McGonigel, Kaufmann, & Johnson, 1991) .

This service coordination is also known as *case management*. Attempts to comply with the federal mandate across disparate service systems, such as

education and health care, have actually seemed to cause more confusion for families. One study of parents struggling with multiple service systems reported, each major system (e.g., the health plan, social services, and school) typically had a separate case manager that did not communicate or coordinate with other case managers . . . furthermore, parents reported high frequency turnover rates among case managers. Families expressed views such as 'sometimes there are so many people to go through that it seems there's nobody in charge'. (Kelly et al., 2002, p. 286)

Currently there is much remaining work to be done in implementing this component, as disparate funding sources and organizational structures make it difficult for one agent to emerge as the one source of coordination or case management across all services. Hence, there are widely divergent experiences for families with regard to the support of a case manager, and the outcomes of these different experiences have not yet been documented in the literature.

These components of (a) involving families in a team approach, (b) family empowerment, (c) sensitivity to family diversity, and (d) the integration/coordination of services, are cornerstones of the current service delivery paradigm; they are often goals to strive for versus an accurate description of current practice. Regardless of discipline or scope of practice, practitioners at all levels must focus their efforts on these components in order to be effective. As Blackman stated in 2002, "without family support and coordinated community involvement, any single activity will not achieve the goal of optimal development for a given child" (Blackman, 2002, p. 12). This emphasis

on the community level of service delivery is another component of the current service paradigm, and is discussed next.

### ***Building Capacity***

Using the ecological perspective, interventions made at any level of the system are expected to impact all other levels to some extent. Services that are targeted at the community level, versus the family or specific agency level, are described as building a capacity to support family-level changes. This section discusses the community as the focus of change, as well as efforts directed at building and supporting informal networks of support for families with special needs children.

### ***Community as Focus of Change***

Within the social systems view of intervention, not only the child and family but also the surrounding community is now viewed as a potential target for change (Dunst, Trivette, & Deal, 1988). Singer and his colleagues concluded that "the locus of stress is not centered so much in the child as in the family's contacts with the community" (Singer et al., 1993, p. 69). Juggling contacts with multiple service providers in disparate locations within inflexible scheduling protocols is but one stressor experienced by these families. Expectations from center-based services of children and caregivers in order to access services include accommodating (a) distant parking lots, (b) physically restrictive and over-stimulating waiting rooms, (c) lengthy waiting times, and (d) the resulting stigmatizing or insensitive responses of others. Krauss and her colleagues documented numerous system-based stressors that these families encounter in

accessing needed services for their children (Krauss et al., 2001). Stressors specific to mobile military families include the difficulties identifying and accessing appropriate support agencies for their specific needs within each new location—and completing the reams of paperwork required to do so.

One target for change has been the community's view of and approach to families of the disabled. An ongoing shift is occurring away from viewing disability as a pathology, with its resultant social stigma, to an appreciation of the positive contributions of disabled children and to recognition of the strength in family resilience (Singer et al., 1993). Hawkins, Singer, and Nixon (1993) provided a method of working with families that includes the positive adjustment process to disability, which challenges the negative characterizations in previous literature of families stuck in "chronic sorrow and existential aloneness" (p. 318). They further cite Turnbull, Turnbull, and their research associates (1986, 1988, 1989) as leaders in "pointing out that in many studies there are insignificant differences between families of children with disabilities and families of children without disabilities and that many parents and siblings report long-term benefits of having a relative with a disability" (Hawkins, Singer, & Nixon, 1993, p. 318). Harry (1997) provided an excellent discussion of different "parameters of normalcy" (p. 66) across differing cultural groups, and of the barriers to communication and to family support that are created by community members' and professionals' use of differing (stigmatizing) classification terms or standards. Community awareness efforts, such as the provision of normalizing depictions of persons with special

needs in the media, are examples of intervention strategies at the community level.

### ***Informal Networks***

Models of social support have increasingly recognized the importance of informal support networks, such as parent-to-parent support groups and mentoring parents. Extensive research, grounded in social network theory, documents the positive effects of informal support networks on positive parenting and knowledge of community resources (Barton et al., 2002; Cochran et al., 1990; Jones & Neil-Urban, 2003). Wethington and Kessler (1986) made an interesting distinction between *perceived support* and *received support*. The first describes the sense that others are available to help if needed; the second involves the specific activities undertaken by others when called upon for assistance. In their research, these authors explored the mediating effects of each type of support on stress levels and found differing effects for different types of people. They called for further research illuminating differences in the experience of support according to personality characteristics (Wethington & Kessler, 1986).

Brett (2004) further highlighted the individuality of the experience of support from others, framing it as a developmental process for parents of disabled children. She outlined the experience of support as a loss to the sense of competence and role adequacy for many, and described the *journey* that many take on the path to accepting support. What is seen as support to one person is not necessarily support to another.

Since individuals are prone to experiencing support differently, any effective service delivery paradigm must include both formal and informal support options. It is important to include clients in evaluating which types of support are best suited for a particular need at a particular time, and to continue to evaluate with service recipients what is helpful over time.

### ***Summary of Service Delivery Paradigm***

Table 1 provides a concise summary of the paradigm shift that has occurred in the approach to providing early intervention services over the last two to three decades. Duwa, Wells, and LaLinde (1993) also provided several useful charts which highlight the conceptual differences in these two approaches, and that additionally provide strategies for moving one's professional practice from the traditional model to a more family-centered program. Included in their guidelines is the involvement of families in program evaluation activities.

### ***Application of Paradigm to Services for AF Families***

This study seeks to integrate all of the above to inquire of AF families their own evaluations of the current delivery system with regard to their appraised meaning of having a special needs child while serving in the military. Specifically, the items of the survey were developed with these questions in mind: (a) Is the system focused on families, (b) is it sensitive to diversity, (c) is there early identification from multiple perspectives, (d) are natural environments used for assistance, (e) are the services integrated and coordinated, and (f) do they seem to be building capacity for those who use them? While each of these areas could

**Table 1*****Models of Family Support Approaches*** (Singer & Powers, 1993)

<b>Residualist or Safety Net Model</b>	<b>New family models</b>
Controlled by professionals	Family driven
Views families as dysfunctional	Assumes all families have strengths and can learn
Intervenes after families are in crisis	Aims to prevent dysfunction, promote well-being, and ameliorate crises
Devotes resources to out-of-home placements	Devotes resources to family
Focuses on person with disability as client	Views whole family as client
Emphasizes formal programs	Activates informal as well as formal support systems
Invests in remote institutions	Builds local community capacity
Emphasizes pathology	Emphasizes adaptation, skill learning, and viewing families as experts and allies
Emphasizes safeguards against fraud and abuse	Stresses flexibility and rapid response to Need
Serves poor families	Serves across all socioeconomic levels

not be fully explored in the scope of the research described in the following chapters, it is important to couch an evaluative study within the established paradigm for service delivery in the current literature.

Supporting families is not only important toward the goal of delivering specialized services. The Department of Defense also recognizes the value of

supporting families in preserving force strength (MFRI, 2004). The establishment of governmental and private organizations specifically designed to support military families emphasizes the importance of quality of life concerns in retaining a qualified and effective national defense. Attempts made by military community agencies to co-locate and consolidate information and enrollment services in one-stop *in-processing* centers (with appropriate childcare provided) and one-source on-line resources are examples of commendable interventions at the community level. These resources are increasingly standardized and integrated with the internet in response to high mobility rates and lengthy separations of families. Of note is that these internet based *portals* serve to link families directly with resources and with other similar families, bypassing the need for intermediaries and expediting the mobilization of support to and from the families themselves (Jowers, 2005).

#### **Research Specific Literature**

Previous sections have described the shift in the focus of intervention from the child alone, to the family, and specific to the community within which the child is reared. A shift in focus has occurred within research, as well. With regard to early intervention and early childhood special education research, this section will present (a) the state of current research initiatives, (b) research on mobility of military families, (c) gaps in knowledge about military families, (d) ethics and values in social work research, (e) roles for social work in research, (f) directions for future research, and (g) the anticipated use of results of this study and its relevance to social work.

### ***State of Current Research***

Initial research in this general field examined whether early intervention or early childhood special education truly made a difference in children's development and family functioning. After documenting extensive evidence that it does (e.g., Guralnick, 1997b; Thomaidis et al., 2000), "second-generation research" (Guralnick, 1997a) now examines "how much and what kind of intervention . . . children and families [are] entitled to" (Bailey, 2000, p. 74).

It is known that in research, the results that one finds depends on the questions one asks. While some researchers have looked for problems that families of the disabled experience, more now focus on how so many succeed. Gallagher and Bristol (1989) described their approach to research involving "a conceptual model of successful adaptation" in examining "the specific factors related to successful outcomes for families of handicapped children" (Gallagher & Bristol, 1989, p. 301). Second-generation research additionally asks about the differing effects of early intervention on varying groups of children and families under specific conditions (Dunst, Trivette, & Jodry, 1997). Culturally diverse families, low-income families, and single-parent families are groups that have been extensively studied in search of the best types of interventions (Campbell & Ramey, 1994; Gallagher & Bristol, 1989).

Third generation research, according to Bowe (1995a), is that described by White et al., in 1994 that builds on second-generation research. In addition to studying what works, and with whom (Guralnick, 1993), current research additionally asks *where* and *when*. These added emphases recognize the

dynamic nature of families and the importance of including the ecological context within which families exist, or *cultural niches* (Hauser-Cram et al., 2000), when conceptualizing research.

### ***Research on Mobility and Military Families***

No published research was found that was conducted on the early intervention or early childhood special education needs or experiences of mobile military families. Research involving geographic mobility separate from a focus on the military frequently confounds issues of poverty and low education, which are typically not associated with military families. Marchant and Medway (1987) cited several methodological flaws found in research on the effects of mobility on children, including the omission of considerations of socio-economic status (SES), of reasons for moving, and the recency of moves. Ingersoll, Scamman and Eckerling (1989) attempted to control for SES and found no subsequent impact on their findings of negative effects for adolescents, but acknowledged they estimated SES based only on neighborhood location and other indirect means. Heinlein and Shinn (2000) cited the critical nature of controlling for SES in studies of mobility, and did so in their study of older adolescents' achievement in school among the geographical mobile, but this was not specific to military families and does not have direct relevance to outcomes for special needs children.

Finkel, Kelley, and Ashby (2003) did specifically study the psychosocial adjustment of military children (not special needs children) related to geographic mobility. Their findings indicated that moving was not as important as aspects of

maternal functioning and family relationships, lending strength to the need for more research which examines the interaction of all of these factors. They specifically addressed the need to include the length of time in the current location as a key variable.

There seems to be a subtle bias in the literature toward studying families who are geographically stable, perhaps due in part to the challenges of including mobile families in research. While some literature does exist about *transition planning* (e.g., Rosenkoetter, Whaley, Hains, & Pierce, 2001), this typically means helping a non-mobile family prepare for the children's transitions into a different service systems because of their increasing ages. Very little is found in this field regarding helping families navigate a transition from one type of service delivery system to another for the same age child, as in a geographic move. One notable exception is Bailey (2000) who found that "by the time parents of infants move from one state to another and realize the differences, there is very little time before their child (sic) moves into the Part B service system, and thus the considerable variation in infant services is not so evident" (Bailey, 2000). This certainly is not the experience of military families, who move throughout the life spans of their children and are acutely aware of service differences in their new locations.

#### ***Gaps in Knowledge about Military Families***

There exists, then, a tremendous gap in the social work knowledge base and in the early intervention and early childhood special education literature about the needs and conditions of mobile families, particularly military families. It

is not known how these families access services in their new locations, nor the combination of services utilized across divergent sources of care. As mentioned in Chapter I, there is no over-arching data tracking system that captures utilization patterns between public, private, insurance-based, or other early intervention/early childhood special education services. Program evaluation efforts are stove-piped (not integrated across programs used by the same recipients), and major sources of services (such as Medicaid, or Maternal and Child Health Services) that could be studied do not identify which beneficiaries are affiliated with the military. Existent services within the DoD have become increasingly more focused on the administrative requirements of managing military assignments, versus what is understood as case management in social work, deferring these services to the civilian sector.

Since these families are so dependent on the fragmented and complex service delivery system, it is important to examine the effects of service policy and structure on the well being of families and special needs children. Identifying the gaps in knowledge and designing research is consistent with the goals of the DoD, of the Air Force in specific, and with the ethics and values of social work.

#### ***Ethics and Values in Social Work Research***

Shifts in both social work and early childhood research priorities (Hauser-Cram et al., 2000) reflect an emerging value for processual or relational justice (Young, 1990) in the research process, in addition to an ongoing focus for social work on distributive justice (Rawls, 1971). Longres and Scanlon (2001) described the two as "two sides of the same coin: relational justice emphasizes decision

inputs, while distributive justice emphasizes decision outputs, or the results of the decision-making process" (p. 448). Since the goal of research is to inform practice, to be an input to the output, the participation of vulnerable or minority populations needs to be actively recruited in evaluative service research.

This approach is supported by literature in research methodology and the ethics of social work research. Many current strategies recognize the desirability of participants' involvement in the evaluation of programs and services (participatory research methods), as well as in setting the goals of service delivery (Able-Boone et al., 1990; Bailey, 2001; Crnic & Stormshak, 1997; Dunst & Bruder, 2002; Duwa, Wells & LaLinde, 1993; Harrison, Dannhardt, & Roush, 1996; Hauser-Cram et al., 2000). In the current paradigms for both services to children with young families and research methodology, program evaluation is grounded in asking clients or customers directly of their appraisal of service delivery effectiveness. This has been occurring in the fields of early intervention and early childhood special education for several decades, with each new generation of research identifying sub-groups of a broader population that need special consideration. Examples include studies into the effectiveness of services for single parent families, for the poor, and for people of color (Barton, Roman, Fitzgerald, & McKinney, 2002; Campbell & Ramey, 1994; Garcia Coll & Magnuson, 2000; and Halpern, 2001, among many others).

Current values in social work research are further reflected in the types of questions asked. Concurrent with the shift from asking how *do we fix broken children and families* to what kinds of support can we provide to strengthen these

families, research is emerging that focuses on which behaviors of service staff and which factors in the community most favorably support diverse families. Within the shift from professionally driven service models to those more defined by priorities of families, research increasingly involves families in choosing desirable outcomes and in describing what is useful or effective for them. Rather than seeking objective, standardized outcomes to apply to all families and programs, early intervention and early childhood special education research increasingly recognizes the nature of desirable outcomes as specific to each family and community. This may be conceptualized as family satisfaction with services and staff behaviors, measured by directly asking diverse families themselves what works for them in their current contexts (Aytch, Cryer, Bailey, & Selz, 1999; Bailey, 2001).

Attempts to identify desirable outcomes in the early intervention research literature consistently identify family satisfaction with services provided as an appropriate measure (Able-Boone et al., 1990; Harrison et al., 1996; Krauss et al., 2001; McWilliam, Lang, Vandiviere, Angell, Collins, & Underdown, 1993). Given the wide variety of needs, potentials, and cultural differences across all disabled or vulnerable children, it is not feasible or desirable in early intervention to establish standardized (externally derived) measures of success toward which all families and programs should strive. Related to strengthening family functioning and to sensitivity for the diversity of families, it is widely accepted that inviting families to evaluate the services offered from the context of their own

needs and preferences is a valuable method by which to assess programs (Able Boone et al., 1990; Harrison et al., 1996).

### ***Roles for Social Work in Research***

Asking parents what they want from early intervention or early childhood special education is conceptually valid; however, as with any publicly sponsored health or social welfare program, there will never be enough money to provide all of the desired services to everyone who desires them. Decisions must be made regarding the priority populations and the levels of services deemed adequate. In an era of decreasing budgets and increasing privatization of social support systems, early intervention must become increasingly cost-effective and outcomes-based in order to compete for limited funding. Who determines appropriate outcomes has become a topic of debate. Social work's commitment to include the voices of the disadvantaged in social decision-making is reflected in research that asks service recipients what they need and value in service delivery systems. Social work is also committed to processual and distributive equity in decision-making. We recognize the importance of establishing and maintaining viable service structures as part of the greater context of services to individuals and families.

Social workers are well suited for the current mission of the early intervention and early childhood special education fields, which is the integration of societal and individual perspectives of their mutual obligations. The diagram provided earlier of concentric circles provides a schema for understanding the role of social work as one of the mediating levels between notions of the public

interest and the common good. Able to live in both worlds, and well represented in both medicine and education, social workers can bring the *both-and* options to the table as alternatives for *either-or* frameworks so typical in American politics and policy today. Since early intervention policy making is not really about the ends, but rather a negotiation of the means, social workers contribute professional skills and values surrounding the humane process of deliberation (Loewenberg, Dolgoff, & Harrington, 2000). Social work research contributes systematic methods toward greater understanding of needs at all levels of the system.

#### ***Directions for Future Research***

Experts in the field of early intervention research have called for further research in many of the areas described in this chapter. Wolery and Bailey (2002) stated that "Studies are needed to identify family-friendly ways to promote parental competence related to difficult daily routines and complex developmental skills with their children and to promote parent-professional communication" (p. 94). Bailey (2001) suggested some family outcomes worthy of future research, including family perceptions of the early intervention experience to learn whether the family sees intervention as making a difference in the child's life, in the family's life, and whether the family has a positive view of the special service system. In the same article he cited Roberts, Innocenti, & Goetz (1999) who called for the measurement of outcomes related to whether the family received desired services, the level of difficulty obtaining services, and the level of parents' influence over decisions. Turnbull, Turbiville, & Turnbull

(2000) are cited in Bailey's 2001 article as calling for more research on family knowledge or skill outcomes, including information, problem-solving, coping skills, and communication skills.

### ***Use of Results and Relevance to Social Work***

The purpose of social work research is to inform practice and policy. Social work research "gives the field the information it needs to alleviate human suffering and promote social welfare" (Rubin & Babbie, 2001, p. 6). The intention of the researcher in this study was to systematically collect and analyze information that documents the experiences of AF families. By studying their experiences in pursuing and obtaining needed services for their special needs children within a mobile military lifestyle, and by examining the nature of the balance between civilian/military service delivery systems unique to each community, the researcher hoped to present information that will guide future studies and services to support the families. Where there is suffering or inequitable challenges in pursuing benefits for which people are entitled, social workers who listen to those reporting them are better able to promote social welfare. Military social workers who work to promote military family welfare indirectly support continued well being among the fighting force, and ultimately the defense of the nation. Applying research to advocacy enables future practitioners and policy makers to become better stewards of public resources, and provide more effective services to those whom they are entrusted to support. The research described next aims to support these goals.

## **CHAPTER III**

### **METHODOLOGY**

This chapter describes the methods used to address the research questions of the study and is presented in the following sections: (a) *research design*, (b) *data collection methods*, including *sampling strategy, engagement of special needs coordinators, survey distribution methods, key independent variables, and key dependent variables*, (c) *statistical analyses*, and (d) *special considerations*. The research questions are provided again here, as the questions drove the methods chosen:

1. What are the types of special needs currently experienced by children less than six years old who are living with AF families in mainland U.S.?
2. What types of specialized services, provided from which sources (military, private, public), do AF families seek and receive on behalf of their young children with special needs?
3. What challenges do they face in obtaining desired services?
4. What do AF families believe is the impact on the military career of having a special needs child?
5. How satisfied are AF families with the delivery of the services received?
6. How sensitive to military family needs do families perceive their service providers?

7. Do those families who receive services report confidence in their abilities to cope with the demands of rearing a special needs child?
8. How do the answers to these questions vary by geographic location, by the involvement of a case manager or other available supports, and by relevant demographic factors (such as family income, number of adults, or rank)?
9. What do these families say about their experiences pursuing specialized services for children with special needs within a mobile military lifestyle?

### **Research Design**

Given the goals of the study, the theoretical premises, the current state of the literature and of ongoing research priorities cited in the literature, the decision was made to directly survey AF families with special needs children. There is no existing information management system or database that can provide a description of the needs experienced, or of the services pursued by these families, and there has been to date no overarching special needs service delivery effectiveness evaluation endeavor specific to AF families. In order to learn about needs experienced, services pursued and challenges experienced, it was necessary to seek these data from the families themselves. Thus a survey was designed (Appendix B) and AF families with special needs children in select locations were recruited to participate by completing the survey. Further details about how participants were recruited are provided in the next section.

Administering a one-time survey to existing groups with no manipulation of conditions by the researcher can be viewed as a one-shot case study method (Rubin & Babbie, 2001). This design is often depicted as

X                      O<sub>1</sub>

where X represents the occurrence of the special need (and the identification of families who meet the study criteria) and O<sub>1</sub> represents the completion and submission of the survey instrument to the researcher. All participants necessarily completed the survey, or O<sub>1</sub>, in order to be considered a participant in this study. Families were also given the option to request a personal telephone contact by the researcher, either to discuss any questions, or to provide further detailed information verbally. More about the data collection methods is presented in the next section.

### **Data Collection Methods**

A combination of returned written surveys and online responses was used to gather all data for this study. Telephone interviews were offered for any families who chose to initiate contact with the researcher, but no families selected this option. The methods used to identify prospective participants are presented in the next section, *sampling strategy*. The unit of analysis for this study is *child*, allowing families with more than one special needs child to report separately on their experiences obtaining services for each child. The unit of observation and the level at which respondents will be invited to participate is the *family*.

In order to distribute the survey instrument to the target population, the assistance of key personnel at each location was obtained. These persons are the Special Needs Coordinators assigned to each base, and are hereafter referred to as SNCs. Methods used to involve the SNCs are discussed in the section, *engagement of SNCs*. To address the research questions, key variables were identified and operationalized. These are presented in the section entitled *key variables*. That section also provides some discussion of the relationships between the research questions and the key variables identified. Statistical methods used to examine the data collected through the measurement of those variables via the survey instrument are described in the *statistical analyses* section of this chapter. The actual results of those analyses are presented in Chapter IV, *Results*.

### **Sampling Strategy**

A purposive sampling strategy was used for this study. Bases with the largest special needs populations of young children were identified via consultation with the AF Special Needs Program Manager and existing data from DefenseWeb. Additionally, efforts were made to include a variety of Major Commands or MAJCOMs (functional distinctions within the Air Force) and a wide range of geographic regions, to capture the distinct Tricare insurance regions. A list of 25 bases was generated, and military treatment facility commanders and special needs coordinators were contacted at each base on the list. The purpose of these contacts was to explain the study and to encourage key personnel to volunteer to participate. Eight bases were recruited from this effort for data

collection. The sample size was unknown at this planning phase of the research, since it was unknown how many children are located at these bases.

The geographic locations involved in the analyses resulted from the eight bases that volunteered and were not predetermined by the researcher. The bases invited, and those that subsequently chose to participate, represent a wide range of distinct states and regions. At each base, every family that met the study criteria was invited to participate through the SNCs. The eligibility criteria were (a) active duty AF family, (b) enrolled in the special needs program, (c) with a special needs child under the age of 6.

Each SNC (or designee) was first asked to perform a data search of all enrolled Special Needs Identification and Assignment Coordination (SNIAC) Program family records at their location, to identify all families whose special needs family member(s) included a child less than 72 months old (inclusive of all ages less than 6 years old) as of the specified date 01 Jan 2005. The researcher carefully instructed all SNCs that the identities of these families must remain known only to the SNC, and not be provided to the researcher by the SNC. A log was provided to SNCs for identification and recording of selected families to be used during the study.

The SNCs then reported to the researcher the number of *children* (younger than 6) represented in the database who met the criteria, and that number of study packages (plus a couple extra surveys) were forwarded to the SNC for distribution to the identified families. Mailing envelopes, labels, and self-addressed, postage-paid return envelopes were included in the study packages

forwarded to each participating base. Additionally, the researcher provided a sample press release article describing the study which base SNCs could tailor with their own contact information and publish in local base newspapers, inviting participation from appropriate families. The next section discusses methods used to engage the SNCs in the study process.

### **Engagement of Special Needs Coordinators**

Respondents were recruited through the base level Special Needs Coordinators (SNCs) at the targeted bases. By AF regulation, every AF base has a SNC assigned for the purpose of coordinating assignments and other military-related functions involving sponsors of special needs family members. The researcher contacted every base SNC (and others in the chain of command, if necessary) to request assistance in recruiting respondents. The study was described to SNCs by telephone and e-mail prior to initiation of the study, and again by a letter that accompanied the study materials mailed to SNCs. A letter was also sent from the AF Special Needs Program Manager, LtCol Moseley, to each invited medical treatment facility where the SNCs are employed. This letter provided information to local commanders about the study being conducted, and that their bases were invited to participate.

The involvement and engagement of the SNCs was recognized as a critical part of the data collection process, and a variety of incentives were considered. Differing perspectives of institutional review boards at the researcher's university and within the Air Force were identified, and the decision was made not to offer any incentives of monetary nature. Each SNC was told

during the planning phase and again at the initiation of data collection how important their participation was, and how their efforts would be recognized by letters of appreciation signed by key figures in their AF chain of command. Regular contacts from the researcher by telephone and e-mail with SNCs additionally reinforced the researcher's appreciation for their efforts.

### **Survey Distribution Methods**

Each SNC was asked to number the eligible participants for response tracking purposes, using the log sheet forwarded to each SNC by the researcher. The appropriate number of study packages was forwarded to each SNC with envelopes and labels to use for mailing study packages to potential respondents. Each study package was coded by base and number prior to distribution to SNCs for presentation to eligible families; this code was used on the log sheet. SNCs entered the names and other contact information on the log according to the coded number of the survey package sent to each family. SNCs were instructed to secure this information in the same manner that they secure other sensitive client data. Respondents were given the option to complete the same survey via a confidential website, and were instructed to insert their code number written on the hardcopy survey at the appropriate prompt on the website.

The researcher tracked each returned survey by base and number. Every 2 or 3 weeks during the data collection period, the coded numbers of remaining surveys that had not been returned were reported to the SNCs. These SNCs were asked to follow-up with remaining non-responding families to encourage them to participate, or to get a sense of the reasons for non-participation. After a

maximum of three contacts (including the original invitation to participate) non-participating families were not pursued further.

The study package included the preamble consent form as it was approved by the University of Louisville Human Subjects Committee, by the Clinical Investigations review authority at Wright Patterson Air Force Base, Ohio, and by the AF Surveys Program. Within the package, a self-addressed (to the researcher) postage-paid envelope was provided, adequate for each participant to return the survey materials, with additional comments as desired. Instructions were provided to allow an alternate response option to the same survey instrument via the confidential website.

As mentioned previously, this study surveyed families directly to obtain demographic information, health information, and descriptive reports of experiences that the families had in pursuing specialized services. When families returned the surveys, the researcher was able to assume the participant intended the release of the self-reported information to the researcher, as was explained in the preamble consent. Only the SNC at each location knew the identities of all participants; the researcher only identified respondents by the codes assigned to returned surveys. SNCs are not able to identify which participants provided which data, as the data were aggregated in the *Results* Chapter and in all concluding reports to the bases. SNCs who provided the substantial support requested were sent letters of appreciation for their personnel files, and additional letters of appreciation were sent by the researcher to the SNCs' commanders on their behalves.

## **Key Independent Variables**

### ***Geographic Location—State and Base***

The researcher recruited respondents from volunteering bases in the continental United States. Each participating base was assigned a range of code numbers for the surveys sent from their sites. Thus, the nominal variables of state and the base are evident in the coded identifier. Since there were no two bases that volunteered from any one state, the nominal variable *state* was used as the identifier for geographic location. Public delivery systems for special needs children are designed and implemented at the state level in the continental US, (not by Air Force bases), so this was determined to be a meaningful variable in exploring the answers to the research questions. One of the goals of this study was to learn whether different assignment locations were associated with different service delivery experiences. Seven primary geographic locations fully participated in the study; one of the original locations that volunteered for inclusion was unable to complete the process.

### ***Relationship of Respondent***

Respondents to the survey were necessarily family caregivers for the identified children, and will herein be referred to as *parent* (regardless of their biological or legal relationship with the child). The specific relationship of the parent completing the survey (e.g., mother, father, step-mother) was also obtained, and this measure provided nominal level data.

### **Type of Special Need**

Each respondent was asked to report the primary condition for which the identified child was eligible to receive ongoing specialized services. Needs, conditions, and diagnoses are conceptualized and used herein as comparable terms which all describe the reason that the child requires ongoing professional care. Conditions were reported as diagnoses where they apply, but they don't always reflect a medical label. This measure provided nominal level data. The original intent was to group responses into categories of similar conditions. Then comparisons could be made on the key outcome variables across groups of types of needs. However, the wide range of responses received across a relatively small number of people made meaningful groupings impractical. This is discussed further in Chapter IV. It was determined upon review that the parents' evaluation of the *severity* of the condition, whatever the name of it might have been, would be a better indicator to use in examining the impact of special needs on the families with regard to the outcome variables of the study.

### **Severity (*Impact on Child, Family, Career*)**

Each respondent was asked to report the perceived level of severity for each reported condition, according to three dimensions or areas of impact. Respondents rated the impact of the condition as having a mild, moderate or severe impact on the functioning of the *child*, the functioning of the *family*, and on the *career* of the service member(s) in the family. Subjective measures of perception were desired, as compared to standardized assessments of what descriptions justify the terms *mild*, *moderate*, or *severe*. According to the

literature discussed in Chapter II, the *perceived* impact is more likely to affect family decision making, as opposed to an outsider's assessment of the severity. Three ordinal level variables were therefore used to assess the severity of the child's condition (impact on child, family and career). Severity of impact on child and family are used primarily as independent variables, and severity of impact on career is used primarily as a dependent variable.

#### ***Age of Child***

This variable was calculated by the researcher and captured ratio-level data. Using the CTIME function of SPSS, the number of days between the date of birth of the child and the date of the response was calculated, and divided by 365.25 to obtain the ages of the children in years. The dates of birth were asked to a.) ensure respondents were providing information on the target population, and b.) assess if there were any relationships between the ages of the children and the outcome variables.

#### ***Time Variables***

Certain lengths of time that had particular meaning to this study were either directly asked of respondents or calculated using the method described in *Age of Child*. Each of these measures provided ratio-level data. These were measured to allow exploration of potential relationships with the key outcome variables.

#### ***Time Known of Condition***

Review of the literature and experience with families indicated that the nature of a family who has just learned of their child's condition is much different

than that of a family who has known for an extended time. With time comes more knowledge of what to expect from both the child and the delivery system, as well as increased networks of support or ability to access services related to the special need. For these reasons, parents were asked the amount of time since they learned of the child's condition, reported in years or fractions of years. These data are ratio level.

#### ***Time Enrolled in EFMP/SNIAC Programs***

These programs were mentioned in Chapter II as forms of support to special needs families by the Air Force. The Exceptional Family Member Program (EFMP) was designed to integrate medical and social work services with personnel functions, sharing information in order to ensure family members were not relocated to states or countries that did not have the necessary services available. It has recently been transitioned to the Special Needs Information and Assignment Coordination (SNIAC) program. SNIAC directly focuses on assignment coordination processes only, with traditional social case management services no longer included. Whereas EFMP Officers were almost exclusively masters-level social workers, the Special Needs Coordinators (SNCs) are typically administrative technicians. These changes were due in part to the desire of the Department of Defense not to replicate functions already performed both by Tricare's Persons with Disabilities Program and by state programs.

Similar to the previous discussion, those families who have been enrolled in the special needs service programs of the Air Force for a longer time are qualitatively different than new enrollees. Examples of ways they are different

include having (a) direct experience with career impact (or no impact) vs. anticipated or perceived career impact, and (b) increased ability to navigate service delivery systems in a mobile lifestyle. Ratio-level data were calculated using the reported dates of response to the survey and dates of enrollment in the program. Since many families did not remember the exact day they enrolled, but did remember the month and year, the first day of the month was substituted for all calculations where the day was missing.

It is important to note that those families who were enrolled in EFMP prior to its change to SNIAC were automatically enrolled in the new program. Since enrollment is at the family level, it is possible for a length of enrollment to be longer than this child's age.

#### ***Time on Station***

Just as in previous discussions and evident in social network theory, the length of time one has spent in a particular location is likely to impact one's ability to access services there. Time on station was calculated using date of response and date of last move, and provided ratio-level data.

#### ***Reluctance (Concern) to Enroll in SNIAC***

Due to the respondent recruitment methods, all participants were necessarily enrolled in the Special Needs Identification and Assignment Coordination program (SNIAC). This program identifies sponsors who have a special needs family member in order to ensure that no family member is relocated to a location that does not have services available for a documented need. Historically, service members have been concerned that having a "Q-code"

in the personnel system would limit their ability to compete for desirable assignments. SNIAC recently replaced the Exceptional Family Member Program (EFMP), and families who were enrolled in EFMP were automatically transferred into the SNIAC. Families who have recently enrolled did so into the SNIAC. Therefore the question is worded to include reluctance to enroll in either program.

In order to maximize understanding of this survey question, it was worded *how concerned was the sponsor about the AF career at the time of enrollment*. Thus the variable is named *concern to enroll*. It was anticipated that respondents would reflect a wide range of perceptions and concerns about the potential for negative career impact based on the additional processes required for assignment determination for these service members. This variable was designed to capture ordinal level data using a Likert type scale, as well as the range of concerns obtained through qualitative information within a confidential reporting opportunity. Content analysis was planned to report themes identified; however, this was not elaborated upon by any of the respondents.

#### ***EFMP Move***

Respondents were asked if they were relocated from their previous assignment due to lack of availability of services in that area. This was asked as an indicator of having already directly experienced significant challenges with regard to accessing services, and of possibly having some perception of career impact due to the premature ending of the prior assignment. This nominal level

measure was used to explore possible differences in outcomes and perceptions based on whether the family had recently experienced this hardship.

#### ***Case Manager, Helpfulness, and IFSP***

Respondents were asked to report if they were working or had worked in their current location with a case manager, and if so, to describe the employing agency. Where a case manager was reported, respondents were encouraged to rate the perceived usefulness of this relationship in supporting the family's needs. These families were then asked to describe how the case manager was helpful to them, or not helpful. Thus in measuring this construct, four separate variables were identified and operationalized. The presence of a case manager is nominal data, the employing agency is also nominal and allowed grouping by type of agency, and the perceived usefulness of the case manager in helping the family obtain services was captured in ordinal data for each respondent. Then, using content analysis, themes were identified, grouped and counted from the nominal variable *how the case manager is helpful*. The themes reported are presented and described in the results chapter using both quantitative and qualitative methods.

A fifth related nominal-level variable is whether the respondent's child has a current *individualized family service plan* (IFSP) or *individualized education plan* (IEP). IFSPs are used for the youngest children; IEPs are used for older children. Both are direct mandates of the federal legislation found in IDEA, the driving force for this service sector. It is the case manager's responsibility to

ensure the development of the IFSP/IEP with the active involvement of the parent where a disability is identified that will require ongoing services.

By asking families if they have an IFSP or IEP, this does in part assess the effectiveness of the case manager where there is one. It also is an indicator of the level of parental awareness about their child's service needs. Parents were given three choices to respond to this item: yes, no, and I don't know. The third response is a particularly telling indicator that the parent has not been informed by anyone about this service tool, or actively involved in the formal process for planning services. It is important here to acknowledge the threshold for disability identification is lower in the military community than it is in the public, state-based, early intervention and early childhood special education service systems. Therefore, it is easily possible for families to be enrolled in SNIAC but not meet the criteria established by their state for assignment of a case manager and subsequent IFSP/IEP development.

This group of variables was conceived as key correlates to outcomes related to access and satisfaction with services. Based on the literature reviewed in Chapter II, the role of the case manager is seen as essential to the successful delivery of early childhood services where the child's and family's needs are more extensive.

#### ***Other Supportive Parent(s) and Others' Helpfulness***

Respondents were asked to report if they knew at least one other parent of a special needs child who provided information and/or support to the respondents regarding managing the care of a special needs child in a military

lifestyle. If so, they were asked to rate the perceived usefulness of this relationship in supporting the family. For those who reported that they did have others available to provide support, they were asked to describe how these others actually were, or were not, helpful to them. Thus, there are three variables subsumed in this operationalization, one nominal level variable reporting if they did have others to support them or not, one providing ordinal data regarding the helpfulness of the relationship(s) with others, and a third nominal level variable which captured descriptions of the help. The data from this third variable, *how were others helpful*, were examined using content analysis and themes identified, grouped, and reported using quantitative and qualitative methods.

This measure was included based on the literature review indicating the importance to many of more informal support networks. Chapter II discussed the need to recognize different families' preferences for types and levels of support. These survey items were also included to provide an indicator of whether families think military communities could or should address this aspect of care to respond to mobile families and their special needs children.

#### ***Family Income Level***

Respondents were asked to report their total family incomes, including an indication of whether they live in government housing. This distinction is important to adjust incomes for comparison across families, since those not living in government housing receive an allowance that is usually included in calculations of family income. Conversely, those living in base housing would appear to have significantly lower incomes than their off-base counterparts

without proper adjustment for their free housing. For standardization, families were asked to report their income on a monthly, after taxes, basis since this was believed to be the easiest for families to reliably report. This figure was then adjusted by the researcher if the family reported the amount of housing allowance received for off-base housing.

A measure of family income was included in order to allow comparisons across the range of financial resources. In part, these ratio-level data provide an indicator of socio-economic status. Additionally, they are used to explore the proportion of out-of-pocket expenses to family income reported by respondents to more fully examine challenges they experience.

#### ***Other Demographic Family Variables***

The following demographic data were requested from respondents: (a) the number of adults living in the family (related to protective factors and available service-pursuit resources), (b) the number of children living in the family (also related to protective factors, demands on parents, and available resources), and (c) the rank of the child's sponsor (an established measure in the military that reflects aspects of socio-economic status, age, and experience with military life).

The literature indicates that all of these variables contribute to an understanding of the possible relationships among the primary research variables. For example, protective factors that increase family resilience, family quality of life, and early intervention outcomes include the regular availability of more parents or caregivers, smaller family size, more financial resources and extended social networks, which are developed over time (e.g., Garbarino &

Ganzel, 2000; Osofsky & Thompson, 2000; Werner, 2000). These factors were discussed more fully in Chapter II. Including these data in the study helped to place each family in an ecological context and to allow exploration of possible relationships between contextual variables and reported outcomes.

### **Key Dependent Variables**

It is important to note here that the following variables are conceptualized in some of the research questions as dependent variables, but are also used throughout separate data analyses as independent variables. Given the exploratory nature of this study, the goal was to examine relationships among all variables believed to be of importance in understanding the experiences of AF families with special needs children. These are described in this section but are not limited in their use as dependent variables only.

### **Type of Specialized Services**

Respondents were asked to report the types of specialized services that had been *desired, pursued and received* for the reported condition(s) for the identified child at the family's current base location. Content analysis was used to group responses involving different terms for the same or for very similar services. *Type* refers to the professional specialization, such as physical therapy, regardless of the employing agency of the provider. A wide range of responses were anticipated and received, with multiple types of services reported for many of the special needs children. In order to streamline the instrument and reduce the complexity and time involved for participants, the survey directed respondents to list up to four of the primary types of services desired.

Respondents then were asked to provide detailed descriptions of the other dependent variables associated with each of those four types of service. Elsewhere in the survey respondents were able to list other services (more than the first four) desired/pursued/received without detailed description.

It was important to make the distinctions among types of services, those desired, pursued and received, and to provide respondents with open-ended prompts to describe their experiences in determining which services they desired to receive, which ones they did pursue, and which ones they and their children actually received. Related to the primary research questions, a key part of this study was tracing the individual experiences of families along this linear progression of steps in service access, and identifying which perceived barriers or supports they reported at each step. These are described more fully in the *challenges encountered* variables.

#### ***Sources of Specialized Services***

The structured instrument prompted respondents to indicate if each received service was provided in the military treatment facility (MTF) or by a civilian provider, and provided space and prompts to elicit as much information as possible about the nature of those service providers (state-sponsored, private non-profit, etc). Anticipating that some families would not know all of the details about the nature of the services, this information itself and whatever statements the families provided as ways of explaining the services were used to lend a deeper understanding of what AF families know about the source of services they desire, pursue and receive. Analysis of this variable required both manifest

and latent content analyses to group responses and code the nominal level data obtained.

### ***Challenges Encountered***

Through a combination of open-ended, semi-structured prompts and direct questions, the researcher elicited responses about the types of challenges that families encountered in accessing each desired service. These are described next as a group of variables that were used to explore self-reported experiences. Questions were asked of respondents in order to address the research question *What challenges do they face in obtaining desired services?*

### ***Out of Pocket Expenses***

Although active duty military families often do not pay any significant co-payments for medical services, some programs provided at the community level are authorized to charge cost-shares, sliding scale fees, etc. Additionally there are costs involved with purchasing needed medications and supplies, such as diapers needed well past the typical age of toilet training. Families were asked to estimate their out-of-pocket expenses within the past year related to each type of service described, and also an overall yearly estimate related to all of a child's needs. These generated ratio level data, which were used as indicators of challenges encountered.

### ***Miles Traveled and Hours Invested***

For each received service described, participants reported the number of miles traveled each way for each incident of service use. For each received

service described, participants provided the number of hours spent each month using that service.

### ***Months on Waiting List***

Respondents were asked if they were placed on a waiting list for any type of service described, and if so, the number of months they waited or were still waiting for services. This measure provided ratio level data, ranging from 0 (indicating no wait) to the longest wait reported, used as an indicator of access challenges.

### ***Why not Received***

Participants were asked to describe, for any service desired but not received, *why* they thought that service was not received. Using content analysis, these reports were grouped and coded, generating nominal data that were assigned numeric values. The actual responses are also presented and discussed in the next chapter, allowing both quantitative and qualitative exploration of experiences reported.

### ***Satisfaction***

Likert type response items were constructed that examined respondents' overall satisfaction with the services received. While the construct *satisfaction* has been operationalized in great detail in other studies, it is recognized here that the family's perception of their own satisfaction level is most relevant to the goals of this study. Where qualitative data about satisfaction with services were provided, these reports were explored using content analysis. This inquiry was designed to capture a brief measure of the service experience in combination

with many other aspects. A *satisfaction with service* evaluation could easily be a follow up study to the current research in its own right.

### ***Access Confidence***

A brief description of what this valued outcome of early intervention and early childhood special education services entails was provided on the survey. Parents were asked to rate, on a Likert type scale, how confident they felt finding and obtaining needed services in their current locations. This is believed to reflect aspects of early intervention or early childhood special education services received that incorporated empowerment of families, providing needed information, and the related service components outlined in chapter two. This measure produced ordinal level data, and is used to partially address the research questions related to service outcomes and families' overall experiences in their current locations.

### ***Coping Confidence***

Similar to the previous variable, parents were asked to rate how confident they now feel in coping with future challenges, a valued outcome identified in the literature, and related to the construct of *hope*. Asking this question separately from the previous one also reflects the understanding that the family will probably not remain at the current location and will seek services in a different place in the future. This measure produced ordinal level data, and was designed to address the research question *Do those families who receive services report confidence in their future abilities to cope with the demands of rearing a special needs child?*

### **Sensitivity to Military Families**

Parents were asked to rate how sensitive or considerate service providers in their current locations were to the unique needs and lifestyles of military families. This was intended to capture the perception of cultural sensitivity to the military family culture. This measure produced ordinal level data, and was designed to address the research question *How responsive to military family needs do families perceive their service providers?*

### **Likelihood of Leaving Military Service Due to Special Need**

Families were asked to rate the likelihood that they would soon leave military service as a result of the stress or challenges faced in pursuing services for their children in a military lifestyle. This was intended to reflect the perceived role strain experienced by the parents, with higher likelihood reported indicating the highest perceived role strain. These ordinal data were considered a measure of the primary outcome variable for this study.

### **Summary of Key Variables**

The key variables are summarized in Table 2 which includes the levels of measurement, and their primary use in this study. The next section addresses the types of analyses used to answer the research questions.

### **Statistical Analyses by Research Question**

In order to address the first research question, (a) **What are the types of special needs currently experienced by children less than six years old who are living with AF families in mainland U.S.?,** the researcher conducted both manifest and latent content analyses. The original intention was to group the

**Table 2*****Summary of Key Variables***

Variable	Description	Levels of Data	Use in Analyses
<b>Primarily Independent Variables</b>			
Geographic location	Name of state and Tricare region	Nominal	IV
Relationship respondent	Parental role with child	Nominal	IV
Type of special need	Name of condition or diagnosis	Nominal	IV
Severity - child	Perceived impact of need on child, rated on 1 – 3 scale	Ordinal	IV
Severity - family	Perceived impact on family, rated on 1 – 3 scale	Ordinal	IV
Severity - career	Perceived impact on career, rated on 1 – 3 scale	Ordinal	IV/DV
Age of child	Age in months and years	Ratio	IV
Time known of condition	Years parent has known of need	Ratio	IV
Time enrolled	Years in EFMP/SNIAC	Ratio	IV
Time on station	Years at current location	Ratio	IV
Sponsor 's concern to enroll	Level of concern for career at time of enrollment in AF programs, rated on 1 – 5 scale	Ordinal	IV/DV
EFMP Move	Recent experience with access hardship/career impact	Nominal	IV
Case manager	Do they have a case manager (and formal, professional support)?	Nominal	IV
CM helpfulness	If so, how helpful is s/he?, rated on 1 – 5 scale	Ordinal	IV
IFSP	Do they have a formal service plan?	Nominal	IV
Other Supportive parents	Do they have informal support?	Nominal	IV
Others' helpfulness	If so, how helpful are others?, rated on 1 – 5 scale	Ordinal	IV
Family income level	Monthly family net income	Ratio	IV
Number of adults	Number of adults in home	Ratio	IV
Number of children	Number of children in home	Ratio	IV
Rank	Highest rank in family	Ordinal	IV

Variable	Description	Levels of Data	Use in Analyses
<b>Primarily Dependent Variables</b>			
Type of service desired	Name of service desired, also grouped into categories	Nominal	IV/DV
Received or not	Whether actually received or not	Nominal	IV/DV
Source of rec'd service	Category of service provider: military, private/public civilian	Nominal	IV/DV
Challenges encountered	Specific items, and content analysis of comments	Varies	DV
Why not	Respondents belief why service not received, content analysis	Nominal	DV
Hours	Hours spent receiving service	Ratio	DV
Miles	Distance traveled to obtain services	Ratio	DV
Cost of service	Out-of-pocket expense	Ratio	DV
Wait list	Months waiting for service	Ratio	DV
Satisfaction with service	Rated satisfaction 1- 5 scale	Ordinal	DV
Total annual costs	Out-of-pocket dollars last year for all expenses related to need	Ratio	IV/DV
Access confidence	Confidence in obtaining services, current location, rated 1 – 5 scale	Ordinal	DV
Coping confidence	Confidence in coping with future demands of need, rated 1 - 5	Ordinal	DV
Sensitivity to military families	Perceived sensitivity of service providers to unique culture and needs of military, rated 1 - 5	Ordinal	DV
Likelihood of leaving military	Self-reported intent to leave service due to role strain or hardship, rated on 1 – 5 scale	Ordinal	DV

conditions reported into nominal categories. However, after much review, it was determined that the range of needs experienced by the children of this study was so extensive that the number of meaningful categories that could be generated was quite large. Given the sample size, this number of categories would not produce cell frequencies appropriate for the types of nonparametric analyses intended. It was therefore determined that the real value of these data lies in the recognition of their broad range. Hence, they are listed in the *results* chapter as they were received. Itemizing the large number of conditions represented by a relatively small number of children lends to an understanding of why tailored services or support groups are not often in place for these mobile and sometimes isolated families.

The second question, (b) **What types of specialized services, provided from which sources (military, private, public), do AF families seek and receive on behalf of their young children with special needs?**, was addressed by asking respondents on the structured questionnaire to report the types of services desired, pursued and received. Content analyses were used to group the individual responses into categories that would be useful and meaningful in data analysis. The researcher calculated the proportion of services actually received to the number desired and reported this by type to explore any potential trends according to the type of service pursued. Frequencies of all responses are provided, as well as the resulting groupings from content analysis, in the *Results* chapter.

Respondents provided the source of the services when describing services actually received. They were offered forced choices of military treatment facility, private civilian facility using insurance, public/government provided, other, and open response opportunities to provide comments about the source of service if needed. Where necessary, content analysis was used to identify the source from comments submitted. Frequencies of responses are provided in the *Results* chapter.

The third question, (c) **What challenges do they face in obtaining desired services?**, was addressed using aggregated responses to specific items on the survey instrument. These were costs by service, total annual out-of-pocket expenses, distances traveled, lengths of time on waiting lists, number of adults in families, and number of children. Ranges and means of data received are reported for the entire sample. For service-related challenges, frequencies and means were again reported, grouped by service type, service source, and geographic location. Kruskal-Wallis one-way analysis of variance by ranks was used to determine if significant differences existed among the groups. Wilcoxon-Mann-Whitney tests, also called Mann-Whitney U in later references, were used to learn whether those respondents who reported working with case managers showed significantly different levels on the challenge outcome measures than those who did not.

Another method used with Question 3 was content analysis to explore responses to open-ended prompts. Where services were desired but not

received, participants were asked to describe *why not*. Groupings were based on the responses received and themes mapped, showing frequencies of responses.

The fourth question, (d) **What do AF families believe is the impact on the military career of having a special needs child?**, was addressed using the perceived severity of impact on military career, reluctance to enroll in SNIAC, and likelihood of leaving military service. Each of these variables captured ordinal data as outcome measures. Non-parametric tests of group differences, Kruskal - Wallis and Mann-Whitney U, were used to assess group differences in these outcome variables, examining potential effects of rank (grouped), and whether they had already experienced a relocation due to unmet special needs (EFMP move). Correlations were used to examine possible relationships between key independent variables such as severity of the condition (impact on both child and on family), lengths of time enrolled in programs, and time on stations, with regard to the ordinal outcome variables assessing perceived career impact using the Spearman rank-order correlation coefficient, also called Spearman's rho, with significant results reported.

To address the fifth question, (e) **How satisfied are AF families with the delivery of services received?**, the overall range and mean of satisfaction levels reported are described. Then, the satisfaction scores for each type of service received by respondents were compared using Kruskal-Wallis to look for group differences in satisfaction according to geographic location, type of service received, the source of the service, the support of a case manager, or support of others. Spearman's rho was used to explore possible relationships between

severity of need and satisfaction levels, between challenges reported and satisfaction, between time on station and satisfaction, and between family monthly income and satisfaction for the entire sample.

The sixth research question is **(f) How sensitive to military family needs do families perceive their service providers?** This was answered through analysis of the variable sensitivity to military families. The range and mean of all responses received is reported. Kruskal-Wallis was used to examine any group differences between type or source of service and perceived sensitivity to military families, and between geographic location and sensitivity to military families. Spearman's rho was used to look for possibly significant relationships between severity of need, time on station, or family income level with perceived sensitivity to military families.

The seventh question is **Do those families who receive services report confidence in their abilities to cope with the demands of rearing a special needs child?** Two items, access confidence and coping confidence, were used to answer this question. One pertains to the perceived ability in the immediate future, in the current location, to obtain needed services; the second addresses the more general perception of future ability to cope with the demands of the special need. The ranges and means of responses received on the Likert-type scale are reported. The database that was created according to service incidents was split according to whether the service was actually received, and the Mann-Whitney U test was used to compare groups according to both reported current access confidence and future coping confidence. Kruskal-Wallis was then used

to examine possible group difference in the relationships between severity of need, types or sources of service, and geographic location. Mann-Whitney U was used to explore potential differences in these access and coping outcome variables according to whether a case manager was involved, and according to whether informal supports were available. Spearman's rho was used to correlate measures of severity of the need with the two confidence variables, as well as time on station (familiarity with community) and family income level. Significant results are reported and further discussed in subsequent chapters.

The eighth question is (h) **How do the answers to these questions vary by the severity of the need, geographic location, by the involvement of a case manager or other available supports, and by relevant demographic factors (such as family income, time in community, or rank)?** The nature of this question was reflected throughout analyses of the other questions. Given the data obtained and the exploratory/descriptive nature of the study, measures of association and measures of group differences were used as appropriate to identify relationships among pertinent variables for the responding sample, as described previously.

The ninth and final research question is (i) **What do these families say about their experiences pursuing specialized services for children with special needs within a mobile military lifestyle?** Opportunity for open-ended comments and responses were purposely provided in the survey design to elicit descriptions of family experiences relevant to the stated goals of the study. An example is the question asked of participants to describe *how* the case manager

or others were helpful, or not helpful. Wherever additional comments were provided anywhere on the survey, these statements were reported in order to tell the stories presented by participants. Where appropriate, content analysis was used, and responses are reported, either individually or aggregated by themes, in the *Results* section. Chapter V, *Discussion*, provides some interpretation of the data received in the context of the study questions.

### **Special Considerations for the Protection of Study Participants**

All of the commonly accepted principles for the protection of study participants apply to this study population. Even though the research involved information about children and their health status, this was not seen as a study that required additional review for vulnerable populations since the children themselves never directly interacted with the researcher or the research process. A statement was inserted into the informed consent form, returned to the researcher, in which the respondent confirmed their legal status in relationship to the child and their legitimate right to provide health and other information regarding the child. All pertinent HIPAA regulations were followed.

Additional considerations to avoid the perception of coercion to participate were required due to the norms of the military community and due to the potential for dual relationships with the researcher. In order to establish the legitimacy of the study with prospective participants, invitation letters were sent both to Military Treatment Facility Commanders and to SNC staff that were signed by a well known authority figure in the service delivery system, LtCol Moseley, the Consultant to the AF Surgeon General for Special Needs Families. Additionally,

those who approved the study within the AF research system were identified to potential respondents. Given the method used for recruiting respondents via the SNCs, special considerations for clarifying the roles of these persons with regard to the study were addressed for potential respondents.

Because these figures carry extensive authority in the AF community, and because they may be viewed as service gatekeepers with the potential for retribution against respondents and non-respondents, it was important in this study that additional statements of protection were made in the preamble consent. Examples include statements that none of these key individuals would be informed of the identities of study participants by the researcher, and that neither participation nor non-participation would affect their access to future services, either positively or negatively.

Since the name of the researcher was provided to potential respondents, additional considerations were needed regarding the possible prior knowledge of the researcher by those invited to participate. Special emphasis was placed on the researcher's role of doctoral student and researcher in this study, versus clinician or officer, as might be previously known by potential respondents. The rank of the researcher was not mentioned anywhere in the study materials to avoid any perception of use of authority in requesting participation. It is believed the methods used adequately and appropriately protected the respondents, while obtaining data that were useful in addressing the study questions.

## **CHAPTER IV**

### **RESULTS**

This chapter presents the data received from respondents based on the questions asked, and describes the analyses used with the information received.

First are a report of the response to the study and a global description of the sample. Then a description is provided about the respondents that made up the study sample, including demographic information and frequencies reported on individual key variables. Next, each research question is presented, including the analyses used to address that question and results found. Pertinent results are summarized in each separate section according to the research question. Finally, an overall summary is presented regarding the important findings of the study, which will lead to the *discussion* of Chapter V.

#### **Response Rate and Sample Size**

A total of eight bases agreed to participate in the study, and seven bases were able to generate responses through a combination of mailed and online responses. One base Special Needs Coordinator experienced personal hardships during the data collection period and subsequently was unable to devote the level of attention needed to generate responses from that base. The states represented in the received responses are California, Mississippi, North Dakota, New Jersey, New Mexico, Texas and Virginia. A total of 47 persons

responded to the invitation to participate, a lower response rate than originally expected. However, the rate of response was relatively consistent across the bases. The range of response rates was 8% to 30%, with an average of 15% received from the seven bases.

Ongoing inquiry to the Special Needs Coordinators (SNCs) indicated that non-response was due in some measure to the mobility of the target population. Based on discussions with the SNCs, approximately 10-25% of identified eligible participants had moved, or were preparing to move shortly, during the processes of identification and invitation to participate. Additionally, a proportion of non-responses were believed to be due to the deployment of the service member, with the resulting increase of role responsibilities for the remaining parent precluding participation. Some potential respondents indicated to the SNCs that even though they had not deployed or moved, the departure of their colleagues from their work centers had generated an increase in workloads to levels that prevented their own participation in the study. Another response received by some SNCs conducting the requested follow-up contacts with non-respondents was that they were relatively happy with how things were going for them, and therefore were not motivated to expend the effort necessary to complete the survey. After consideration, it is believed that this population is a difficult one to engage in research within a limited time frame, as was the case for this study. The very issues described in Chapter II which led to the identification of this population as a vulnerable one worthy of study (work/family conflicts, occupation in a *greedy institution*, increased parenting challenges due to pursuing

specialized care in a mobile lifestyle, etc), also made it extremely difficult to engage them for participation in this type of research.

It was additionally recognized that each family represents multiple incidents of desired services, with multiple types of services needed by individual special needs children. After responses were received, a separate data base was created viewing incidents of desired services reported as another unit of analysis. Using this framework, 112 separate service needs were analyzed as a second sample where the question related more to service-related concerns vs. child-related topics. Throughout the remaining chapters, the unit of analysis and which of the two distinct databases was used will be addressed when reporting results.

### **Description of Responding Sample**

#### ***Demographic Information about Families and Children***

This section describes the study sample (persons, not services) according to (a) variables that primarily describe the families, and (b) variables that primarily describe the special needs. As mentioned previously, a separate database developed for this study examines the actual services desired. A description of that sample and the frequencies of service-related variables are reported in the section addressing research question two.

#### ***Family Information***

Forty-seven persons responded to the invitation to participate, and each reported information regarding one child. None of the respondents indicated they were participating with information about two or more children, although casual mention of having other children with needs was provided anecdotally in some

comments sections. Additionally, none reported that they did not actually reside with the child described. Therefore, this study represents 47 caregivers who provided the following information about their families. This information helps to frame the context in which the 47 individual special needs children were being reared at the time of the study.

**Geographic location.** Families living at seven bases in seven separate states participated in this study. Since the military family health care management system (Tricare) is operated in three regions in the continental U.S., these regions were used as groups of geographic locations for analyses:

Tricare North	New Jersey and Virginia (n = 26)
Tricare South	Mississippi and Texas (n = 17)
Tricare West	California, New Mexico, and North Dakota (n = 4).

Unfortunately, the base that was unable to generate responses was in the western region. More responses were received from Virginia than any other state.

**Relationship of reporting caregiver to child.** The large majority of respondents were mothers of the special needs children (n = 38, 81%), with other respondents reporting that they were fathers (n=8) or married to the mother of the child (n = 1). None stated they were a step-parent to the described child, even though that response option was provided.

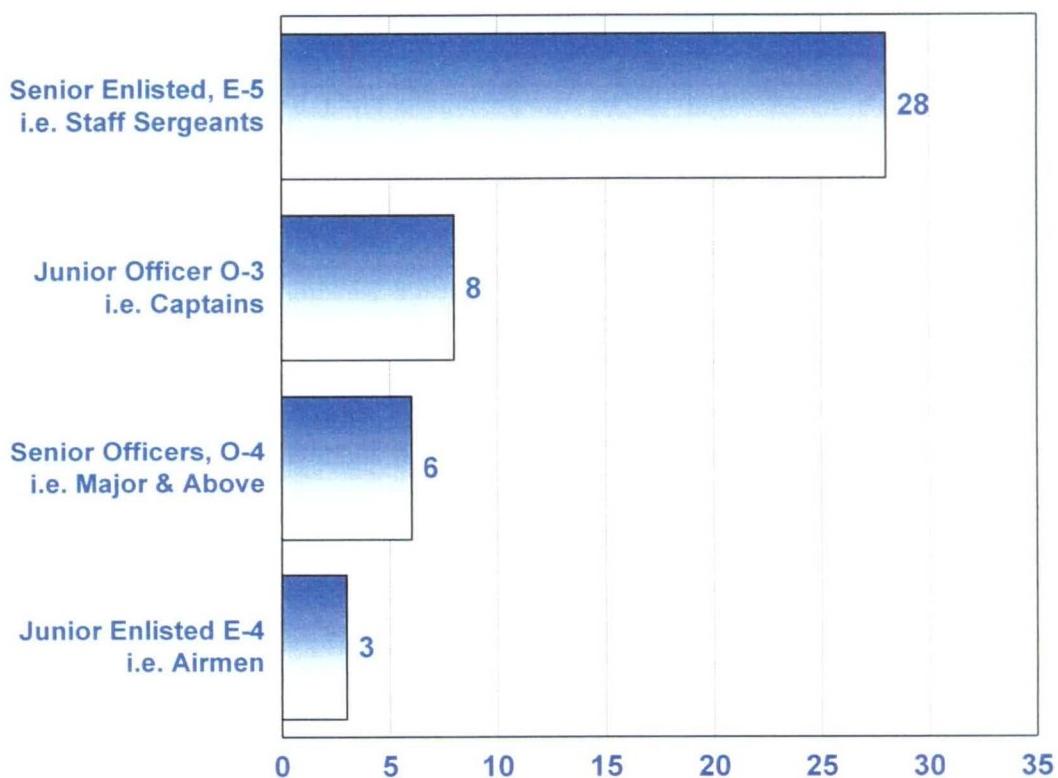
**Number of adults.** Most of the participants indicated that their families consisted of two adults (n = 40). Three respondents indicated they were the only adult in the home, likely single parents, and two indicated there were three adults

in the home, possibly indicating the presence of extended kin residing with the child. Two respondents chose not to provide this information.

**Number of children.** Eighteen respondents indicated that the special needs child was the only child at home; 16 reported that there were two children. Other responses included three children ( $n = 6$ ), four children ( $n = 4$ ), and eleven children ( $n = 1$ ). The same two participants chose not to provide information about the number of children as chose not to report the number of adults.

**Rank of sponsor.** The majority of the sample reported their rank as E-5 (Staff Sergeant) or above in the enlisted ranks ( $n = 28$ , Figure 3). The next largest category reported was junior officer, O-3 (Captain) or below, ( $n = 8$ ). Six respondents indicated they were senior officers (O-4, Major, or above), and three stated they were junior enlisted, E-4 (Senior Airman) or below. Two (the same two as described previously) chose not to provide this information. Figure 3 presents this distribution of ranks among the response sample.

These proportions are believed to be reflective of the distribution of ranks across the Air Force for those who have children. According to MFRC (2005), junior enlisted personnel (E-1 through E-4) have 13% of the children identified as military dependents, and junior officers (O-1 through O-3) have 9%. While these two categories were reversed in terms of which had the larger proportion of children represented in this study, the proportions are believed to be within the range approximating the population of AF members as a whole. Just as in this study, senior enlisted members (E-5 through E-9) have by far the largest



**Figure 3. Ranks of Air Force members whose children with special needs are represented in the sample.**

proportion at 64% of the population of AF children, and senior officers (O-4 through O-10) have 14%. Table 3 shows a comparison between the MFRC figures and the proportions participating in this study by rank groups (aside from the two respondents who chose not to provide their rank information).

**Family monthly take-home income.** Seven participants chose not to report their monthly family income. The dispersal of incomes reported across the remaining 40 participants is somewhat evident from the range of ranks reported. However, it is important to remember here that family income includes that of a working spouse or other sources of income such as child support. No direct

**Table 3**

***Comparison of Number and Percentages in Rank between AF and Current Study***

<b>Rank Group</b>	<b>Number in This Study</b>	<b>Percentage in This Study</b>	<b>Number in the Air Force</b>	<b>Percentage in the Air Force</b>
E-1 – E-4 Junior Enlisted, e.g. Airmen	3	6.7	21,629	12.8
O-1 – O-3 Junior Officers, e.g. Captain & Below	8	17.8	15,867	9.4
E-5 + Senior Enlisted, e.g. Staff Sgt & Above	28	62.2	107,551	63.8
O-4 + Senior Officers, e.g. Major & Above	6	13.3	23,295	13.8
<b>Total</b>	<b>45</b>	<b>100.0</b>	<b>168,342</b>	<b>*99.8</b>

\* less than 100% believed due to rounding, figures taken from MFRC

connection between rank and income was found, particularly in the middle two groups of ranks shown above. The range of monthly incomes reported was from \$1,040 to \$8,313. The mean monthly income was \$3,274, and the standard deviation was \$1,735.

***Age and time variables.*** These respondents provided information about their children's ages, the lengths of time that the family had known about the conditions, that they had been enrolled in special needs programs, and how long they had been living in their current locations (time on station). The sample recruitment criteria included that age of the child must be 6 years old or less at the time of data collection. Forty-four percent of the children described were less

than 3 years old at the time of the study, 56% were 3 or older. Fifty-seven percent of the sample had known of their children's special needs for less than 3 years, the remaining had known for 3 years or more. About half had the youngest children and about half had the oldest children of the sample, about half had known of the condition for less than 3 years and about half had known for more than three years. Table 4 shows that the average time enrolled in programs was 2.15 years, the average time on station was 2.62 years. The large standard deviation shown for time on station reflects the range from just a couple of months to almost 13 years, with 88% of the sample reporting less than five years on station.

**Table 4**

***Means and Standard Deviations of Age and Time Variables***

	Age in Years	Years Known of Special Needs Condition	Years Enrolled in Special needs Program	Years on Station
Valid <i>n</i>	45	47	44	42
Mean	3.29	2.74	2.15	2.62
Standard Deviation	1.52	1.51	1.50	2.71

***Needs Information***

***Primary special need.*** As discussed earlier, the original intention was to group the needs reported into types of needs that would allow comparisons across groups of needs. However, upon review of the data received, the wide range and also specificity of the conditions reported made this impractical. Attempts to group resulted in either so many categories that cell frequencies

were inadequate for statistical procedures, or so broad as to be meaningless in enhancing understanding of the experiences of families. Therefore, Table 5 shows all reported needs/conditions and the diversity is profound. It is easy to imagine how hard it is for AF families to find support, either within the AF community or in unfamiliar civilian communities.

Headings provided in the table were arbitrarily created by the researcher for clarity. While participants were asked to name the primary need they wished to describe in the study, several respondents listed two different needs. Rather than eliminate one, both are included in Table 5, resulting in 57 special needs/conditions of their children as reported by the 47 respondents.

***Severity of need, impact on child.*** Respondents rated their perception of the severity of the stated need(s), first by the observed impact on the child's daily functioning. A 3-point Likert-type scale response option was provided, offering mild, moderate or severe as options. Not all participants chose to provide this information. Two wrote in that there was absolutely no effect on the child, a response not anticipated in the design of the survey instrument. Among those who selected from the response options given, the mean severity rating (impact on child) found was 1.84, with a standard deviation of approximately 0.78.

***Severity of need, impact on family.*** Similar to the previous item, respondents were asked to rate their perception of the severity of the need(s) as they impact the family's functioning using the same scale. Also as above, some chose not to provide this information. One person reported it did not impact family functioning at all. Among the remaining respondents, the mean severity

**Table 5****Needs/Conditions Reported by Caregivers (*n* = 57)**

<b>HEART CONCERNS</b>		<b>VIRAL/INFECTIOUS</b>	
Severe Aortic Stenosis	1	Acute Ear Infections/Sinusitis	1
Hypoplastic Left Heart Syndrome	1	Unexplained High Fevers	1
Congenital Heart Defect, Congenital Heart, Defect:Truncus Arteriosus1A	2	Cytomegalovirus (CMV)	1
Tetralogy of Fallot w/severe SVT	1		
Heart Murmur	2	<b>CEREBRAL PALSY</b>	4
Ebstein's Anomaly of the Heart	1	<b>DOWN SYNDROME</b>	3
Arterial Septal Defect	1	<b>DEVELOPMENTAL DELAY</b> , or Risk of developmental delays due to prematurity	3
<b>MALFORMATIONS, PROBABLY CONGENITAL</b>		<b>CYSTIC FIBROSIS</b>	2
Arthrogryposis/Club foot	1	<b>AUTISM</b>	2
Cleft Lip/Partial Palate	1	<b>HYDROCEPHALUS</b>	2
Hip Dysplasia	1	<b>OTHER</b>	
Spina Bifida	1	Traumatic Brain Injury	1
Pulmonary Stenosis	1	Shoulder Dystocia	1
Cranial Stenosis	1	Hearing impairment in right ear	1
<b>METABOLIC/DIGESTIVE/NUTRITIONAL</b>		Leukemia	1
D-byfunctional Single Enzyme Deficiency	1	Hinds Syndrome	1
Low weight	1	Intraconal Venolymphatic Malformation of Rt eye (he has a mass in R eye's orbit)	1
Reflux	1	13Q-deletion Chromosome Anomaly	1
Failure to thrive	2	<b>VACTERL syndrome</b>	1
Infantile Anorexia	1	Psychomotor retardation	1
<b>ALLERGIES/ASTHMA</b>		Sickle Cell Anemia Disease	1
Severe Allergies	1	Learning Disabilities	1
Eczema			
Asthma	3		
Chronic pneumonia	1		

rating (impact on family) found was 1.77, with a standard deviation of approximately 0.68 and a mode of 2, moderate impact. Overall, the majority of this sample believed that the impact of their children's needs on the children and

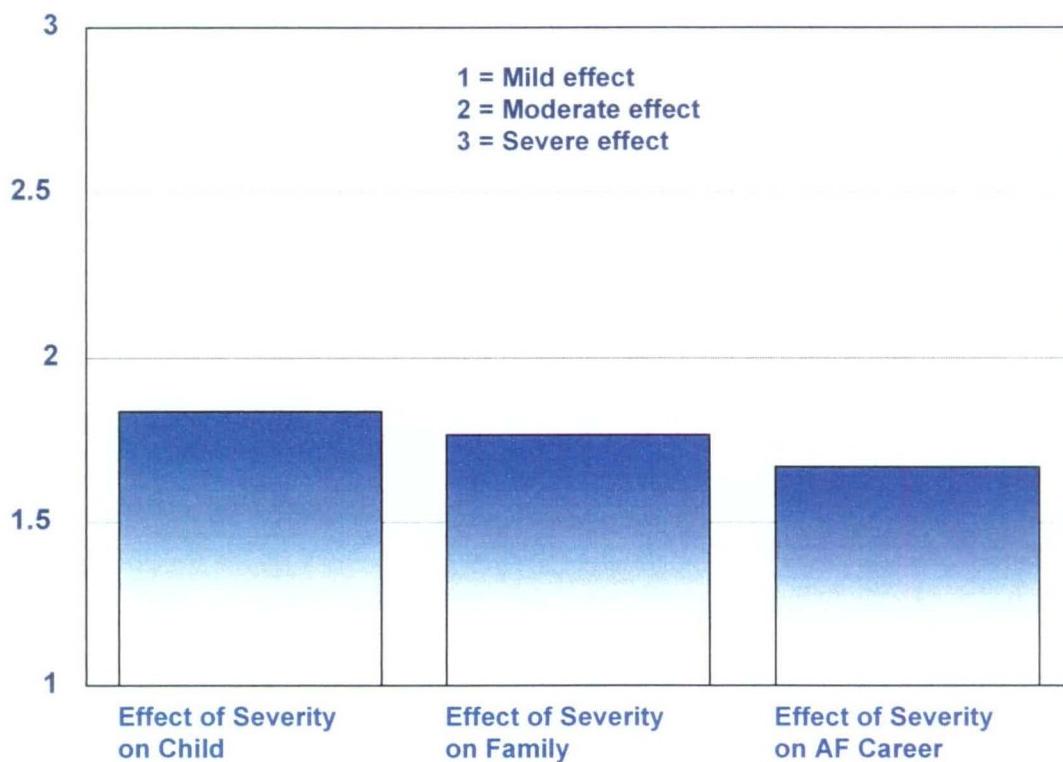
the families was mild to moderate, with some acknowledging that there was a severe impact on either or both.

**Severity of need, impact on AF career.** Unlike the prior two items no one indicated *no impact* when asked to rate the severity of the child's need(s) on the AF career using the 3-point scale. With 4 missing, the mean of the remaining responses about the impact of children's special needs/conditions on the AF member's career was 1.67 on the 3-point Likert scale. Figure 4 shows the means of these three variables related to the severity of the need(s). Therefore, this group of AF families as a whole believed the impact to the AF career was mild or moderate. Group differences among responses to this specific item are presented in the section discussing research question four.

This section has described the group of respondents to present the reader with a general understanding of participants. Next, the specific research questions of the study and findings are examined in detail.

### **Research Questions and Findings**

In the following sections, each individual research question is presented again to lead the discussion of the results found upon analyses of the responses received from the study sample. It is important to emphasize here that due to the sampling methods used, there is no claim to generalizability either to AF families as a whole or to those with special needs children. The results described are specific to these respondents only, and limited by the types of analyses possible.



**Figure 4. The means of severity of impact of the special need on the children with special needs, their families, and the AF members' careers.**

#### ***Question One: Types of Needs***

**What are the types of special needs currently experienced by children less than six years old who are living with AF families in mainland U.S.? As discussed previously, the diversity of needs/conditions was virtually 100% (Table 5). In the AF, the criteria for enrollment in special needs programs is and has been the existence of a condition (medical, educational, psychological) that was likely to require ongoing care by other than a primary care provider (physician, physician's assistant, or nurse practitioner). This is**

obviously quite broad and is intended to be inclusive of a wide range of needs that might not meet the criteria in the public, civilian service sector as a *special need* or disability. The intention of such identification is to ensure that family members are not relocated to states or countries that would not have the needed services available. This wide range of needs/conditions in Table 5 helps to frame the challenge of families and of service providers in developing networks of care that meet the specific needs of mobile children.

#### ***Question Two: Types and Sources of Services***

**What types of specialized services, provided from which sources (military, private, public), do AF families seek and receive on behalf of their young children with special needs?** To address this question, a separate database was developed which listed 112 incidents of desired services as the unit of analysis (versus individual children or families, some reported multiple services). Table 6 shows the full list of responses received regarding types of services desired. From these responses a content analysis was conducted that identified four major types of services. The sources of these services are described after the Types section which is next.

#### ***Types***

The large majority of service types desired and received were physical therapy, occupational therapy, and speech therapy. These, and other allied health services that were reported less frequently (e.g., nutrition or dietician services), were grouped together. The relatively low number of special education-type services ( $n = 4$ ) reported allowed them to be grouped with allied

**Table 6*****Services Desired for Children of AF Members with Special Needs***

Service Needed	f	Service Needed	f
Speech Therapy	16	Informed pediatrician	1
Physical Therapy	13	On base pediatrics	1
Occupational Therapy	12	Off base doctor	1
Physical and Occupational Therapy	2	Adequate care on base	1
Physical, Occupational, Speech combined	2	Specialty Clinic	1
Sign Language	2	Hospitalization	1
Child Dev Specialist, Speech Therapy	1	<b>TOTAL SPECIALTY, MD PROVIDED</b>	<b>27</b>
Feeding Therapy, Nutrition, weight	4		
Special Needs Play Groups	1	Durable Medical Equipment, walker, catheters	3
Developmental Delay Therapy	1	Hearing Aides	2
In home Nursing Services	1	Pulse oximeter	1
Special Education	1	Formula supply and medical supplies	1
Teacher	1	Required Allergy medicines	1
Schooling	1	Botox	1
Monitoring, testing learning related issues	1	All meds on base	1
<b>TOTAL ALLIED HEALTH</b>	<b>59</b>	<b>TOTALEQUIPMENT/MEDICATIONS</b>	<b>10</b>
Surgery, Reconstructive Surgery	3	Counseling	3
Pediatric Dermatologist, Dermatology Consult	2	Behavior/Behavioral Therapy, ABA Therapy	3
Pediatric Allergist, Allergy Consult	2	Behavior Counseling—Family	1
Neurologist	2	Therapy type info to lessen her growth impact	1
Orthopedic Surgeon, Pedi Orthopedic Surgeon	2	Updated info on disease	1
Post surgical monitoring	1	<b>TOTAL MENTAL HEALTH/PARENTING</b>	<b>9</b>
Pediatric Cardiologist	1		
Neurosurgeon	1	Medicaid	1
Pediatric Brain Injury Specialist	1	Money to help with daycare expenses	1
Oculoplastic/Pediatric Ophthalmologist	1	Social Security Disability	1
Pediatric pulminologist and gastroenterologist	1	Help navigating the Tricare system	1
Gastroenterologist	1	Referrals prior to move since wait = 6 months+	1
Pediatric electrophysiology	1	Finding specialists in potential move location	1
Matching bone marrow donor, transplant	1	Civilian childcare, before nursing services	1
Vision therapy through a physician	1	<b>TOTAL OTHER</b>	<b>7</b>
		<b>TOTAL SPECIALIZED SERVICES</b>	<b>112</b>

health services (total n for this category = 59). For the very youngest children not yet attending school, it is reasonable to include special education services with allied health (non-physician) care.

Following these, the next largest type of services received by the sample was for some type of specialty physician care or surgery, such as pediatric cardiology or neurology. Services normally provided by physicians were grouped together in this second category (n = 27). Services described which involved obtaining needed specialized medications or adaptive equipment (e.g., hearing aides or walkers) were grouped in a third category (n = 10). Mental health, behavioral training, family counseling or parenting guidance services were grouped together in the fourth category (n = 9). All other services not previously grouped were combined into an *other* category (n = 7) and include such services as obtaining Medicaid or Social Security benefits, or assistance locating or paying for specialized daycare.

### **Sources**

A great deal of variability exists across the service delivery sector. Some are considered strictly medical in nature, provided by medical treatment facilities and medical providers. Within this category, the size of the base and the capacity of the military treatment facility determine whether family members (non-active duty members) obtain their health care services on base. Where provided on base, these services are typically free of charge to the beneficiary. Some family members receive only primary care on base and specialty care in the civilian sector, some receive both primary and specialty care in the local civilian

communities. Civilian community-based services that are medically necessary are paid in whole or part by the military family health insurance company, Tricare. It is more common for military families to pay co-pays off base than on base.

Allied health and mental health services are also provided on base at some bases, although some are not available on base and are provided off-base in the civilian sector. Within these off base services the sources may again be private (covered by insurance), private non-profit, or publicly provided under federal, state, or local funding sources. Every state is required under IDEA to provide early intervention and early childhood special education services. These must be offered free or at very low cost to recipients through public funding to ensure a free and appropriate public education for all. Just what those services will be and how they are delivered is at the discretion of each state, resulting in wide geographic variability in which services are publicly available.

Due to this variability, the survey instrument prompted respondents to select the sources of the services described. This was important since no single source can identify where these families are obtaining services, and service improvement efforts must of course be tailored to the venue in which the services are provided. Additionally, in order to assess measures of satisfaction or other outcome variables appropriately, it was necessary to first identify the sources of services received.

The majority of received services, 32 of 77 (42%) described under this item, were obtained through civilian, insurance supported, medical facilities. Twenty-two (29%) were obtained through the public/governmental sector and are

believed to be affiliated with state-based early intervention services established under IDEA mandate. Only 17 of the 77 services (22%) were obtained at the medical treatment facility on base, 1 through a private, non-profit organization and 3 listed *other* as the source. These others include such services as childcare, which does not fit into any of the provided response categories. Two respondents indicated they did not know the source of the services received.

While it was not directly asked in the research question, it is also interesting to note the balance of types and sources of services that were desired but NOT received by the respondents. Eleven of the 33 services desired but not received (33%) were allied health services, 10 of the 33 (30%) were specialties typically provided by physicians, 5 were mental health/behavioral in nature, 3 were medications or equipment and 4 were others. When looking at sources of services desired but not received, only 6 separate incidents of service were described by source even though 33 services were listed as desired but not received. Within these 33, 3 were desired at the military treatment facility but not received, 2 were desired at a civilian health care facility using Tricare but not received, and 1 desired of a public or government program but not received. Twenty-seven responses indicated either "I don't know" or left the item blank, which is understandable since they were describing a type of service they desired but did not actually receive.

#### ***Summary of Types and Sources***

Most of the services obtained by the respondents were allied health types of services such as occupational, physical, or speech therapies. The second

largest type of services received and described by these respondents was specialty care, typically provided by physicians. The primary source of these services was in a civilian medical treatment facility or clinic, using insurance benefits; almost half of all services received were from this source. The next largest source of received services (almost 30%) was from public or government programs, and somewhat fewer were provided by military treatment facilities.

This finding is important to the understanding of the challenges faced by mobile military families when arriving in a new location and needing specialized services for a child. The predominance of the service providers (72%) in this study were not affiliated with the base in any way, and were decentralized into the local community. Additionally, the majority of services needed and used by this sample were allied health services, possibly more diverse, more location specific, and less likely to be located in a health care facility than traditional medical/physician-provided specialties. Families must navigate referral systems involving *gatekeepers* (referral authorities under a managed care system), the insurance company (organized at the regional vs. local level), and state-based variances in types of care available, while trying to locate and obtain diverse types of allied health services delivered at the local (unfamiliar) level. The next research question more fully explores the challenges they face in doing so.

### ***Question Three: Challenges***

**What challenges do they face in obtaining desired services?** For each type of service received, participants were asked to describe aspects of receiving that care. They responded with the monthly out-of-pocket costs of using that

service, the number of hours spent on a monthly basis obtaining the service, the distance traveled in miles per service incident, and the number of months spent on waiting lists. These are presented next, with additional measurements of challenges described in the following sections.

### ***Out-of-Pocket Costs***

Respondents provided information on costs for 72 received services and chose not to provide this information for 7 services. Using all information available, the mean monthly out-of-pocket costs reported in obtaining services was \$23.93; however, the standard deviation was \$98.00. Excluding one "outlier" who reported a monthly cost of \$780, the mean monthly cost per received service found was \$13.28, with a standard deviation of \$38.21. Those not accustomed to the extensive health benefits available for military families might be surprised at how low these figures are. This study confirms that out-of-pocket expenses for services received are not a considerable barrier to obtaining care. However, it is important to consider that these data pertain only to services that were received. A significant number of respondents indicated that costs were a factor when desired services were NOT received, probably because they were not covered by insurance benefits or provided on military bases. This issue is discussed again in the challenges section entitled *Why not received*.

### ***Hours Spent***

The time spent actually receiving services might be argued to be a benefit versus a challenge with regard to specialized services. On the one hand, it is wonderful to find a responsive provider who will spend much time with a child

with special needs; on the other, hours taken out of family life spent in the pursuit of specialized services may be viewed as a challenge. The data reported are described here with the understanding that large figures reported are a mixed blessing.

Several respondents indicated they had spent more than 200 hours per month receiving some of the services. Upon review, these include an incident in which the child was medically evacuated from an underserved area and hospitalized for an extended time period (for which the parent reported high satisfaction), one incident of in-home nursing care, and one incident of specialized day care. These situations are seen as relief-providing episodes of service to caregivers and children, and were therefore excluded from analysis of hours as a challenge. Excluding these cases with very high reported numbers for costs, the following information is reported.

The mean number of hours spent receiving described services ( $n = 68$ ) was 8.35, with a range of zero to 100 hours reported. The standard deviation was 16.24. Five persons endorsed zero as their answer, and clarified that less than one hour is spent monthly as the question was worded. Some of these services were received on a more infrequent basis. One person reported 100 hours per month were spent in special education; again, a mixed blessing. Ninety-seven percent reported spending 50 hours or fewer per month obtaining specific services; 80% reported spending 9 hours or fewer per month. On the whole, time, like money, is not a critical factor to these families or seen as a challenge to obtaining services.

### ***Miles Traveled***

Seventy-seven respondents provided a response to the number of miles traveled to obtain services for their special needs children. Of those, two incidents were unusual, involving medical evacuations from a great distance to first obtain hospitalization and surgery, and later to post-surgical follow-up and evaluation of the same child. These two incidents were excluded as outliers in the following analyses regarding miles traveled. Of the 75 remaining service incidents for which this information was provided, a full one-third ( $n = 26$ ) involved no traveling. These services were probably home-based services, the provision of which is emphasized in early intervention service design.

The average distance traveled reported for each service incident was 22.4 miles; the median was 5 miles, and the standard deviation was 46.76. Eight services involved travel of 50 miles or more each way per incident. Thus, many families do not experience travel distance as a significant challenge to obtaining services within this sample, but some do experience extensive travel distances. This is explored further by geographic location in a separate section.

### ***Months on Waiting Lists***

The entire sample of respondents who received services reported that they spent 16 months or fewer waiting for access to that care. All but one case reported they spent 9 months or fewer waiting for a specific service, and a full 50 of the 71 (70%) who provided this information reported no wait or less than 1 month wait. Ten people reported waiting 1 – 2 months, six people 3 – 4 months, and five waited 6 or more months for a desired service. For some, this was a

significant challenge. Given that a typical assignment for many military families lasts 2 – 3 years in one location, waits of 6 months or more can significantly impact a child's course of treatment. It must be remembered that these waits are in the current location, and that these families will probably move again soon, possibly encountering new waiting lists.

#### ***Number of Adults in Family***

This variable is included in the review of challenges families experience in order to address the availability of adults for specialized care giving or general parenting functions. The literature review presented in Chapter II identified single parenting as a significant challenge to obtaining care for special needs children. In this sample, single parenting was not found to be a concern since 40 of the 45 parents who provided this requested information reported 2 adults were in the family; two reported there were 3 adults in the family. Only three, or less than 7%, of the sample indicated they were the sole adults in the family. Of course, it must be remembered that some of those adults included as family members might be currently deployed, or working longer hours to support work centers who have lost members to deployment. This survey did not address how many adults are currently available and actively involved on a regular basis in the care of the child. Notwithstanding, it is believed that this sample represents a higher than typical number of dual-parent families. This may be due to a response feature that single parents might have more demands on their time and might be less likely able to spend the time completing the survey.

### ***Number of Children in Family***

Discussion of this variable is also included under a review of challenges for similar reasons to the previous one. The literature identified the number of children in the family as a potential barrier to obtaining specialized services for a special needs child, with more children in the family increasing the challenge. Of the 45 who responded to this question, 18 reported that the special needs child identified for the study was the only child in the home. Sixteen reported 2 children, six reported 3 children and four reported 4 children. One outlier reported 11 children in the family—one can imagine the challenges met by that family not captured by this study. Twenty-seven of the 45 families, therefore, reported that there was at least one other child to care for in addition to meeting the demands of caring for a special need child. This information helps in understanding the challenges that families encounter to obtain services.

### ***Challenges Examined in Groupings***

Challenges are reported here by type of service obtained, source of service, geographic location, and by whether the support of a case manager was available. Each independent variable is examined across all dependent variables related to challenges.

**Type of service.** Using the Kruskal-Wallis test for group differences, no significant results were found on costs per month or length of time on waiting lists. However, hours spent monthly receiving services and miles traveled each way to obtain services both were significantly different according to type of service received. Using the Kruskal-Wallis test for group differences in hours

spent receiving services, the mean rank for allied health services was 40.30, for specialty MD services the mean rank was 32.88, for mental health/behavioral counseling it was 29.38, for medications and equipment it was 13.10, and for other types of services it was 3.00. The Kruskal-Wallis coefficient was 11.90, df = 4, p = .018, when exploring group differences by type for hours spent. Examining group differences by type of service with regard to miles traveled, the mean rank for specialty MD services was 54.29, for mental health/behavioral counseling it was 48.88, for medications and equipment it was 45.79, for other it was 31.00 and for allied health the mean rank was 28.80. The Kruskal-Wallis coefficient was 21.216, df = 4, p < .001, with regard to miles traveled. The outlying or unusual cases described previously were excluded for all analyses of this type. These respondents reported significantly more hours spent receiving allied health services than other types of service, and traveled more miles to obtain specialty care typically provided by a physician than any other service types.

**Source of service.** The three primary sources of services reported were used for these analyses, with 1 assigned to represent the military treatment facility, 2 the civilian medical facilities using insurance, and 3 the public/government sponsored programs. Using the Kruskal-Wallis test for group differences, no significant group differences were found on hours spent monthly according to the source of service received. However, costs per month, miles traveled each way, and months spent on waiting lists varied significantly based on the sources of services reported, when outlying cases were excluded. The results are as follows.

With regard to costs per month, the mean rank of private civilian facilities was 44.48, of military facilities it was 31.02, and of public sources it was 29.20; the Kruskal-Wallis coefficient was 14.64, df = 2, p = .001. Examining miles traveled each way, the mean rank of military facilities was 42.71, of private civilian ones it was 40.98, and for the public services the mean rank was 20.33; Kruskal-Wallis = 16.33, df = 2, p < .001. Differences found in months spent waiting were found in the private civilian facilities' mean rank was 40.95, that of public services was 37.24, and the mean rank of military facilities was 28.83; the Kruskal-Wallis coefficient was 6.03, df = 2, p = .049.

Civilian medical facilities using insurance were associated with more costs than the other two sources (which are typically free or offered on a sliding scale). Military treatment facilities were associated with more miles traveled each way, and there may be a connection between this finding and the previous one. It makes sense that people might drive further to obtain a free service from a familiar source (the military treatment facility) if it is offered. Regarding months spent on waiting lists, civilian medical facilities followed by public services were the groups with the longest waits, with military facilities associated with the shortest waits.

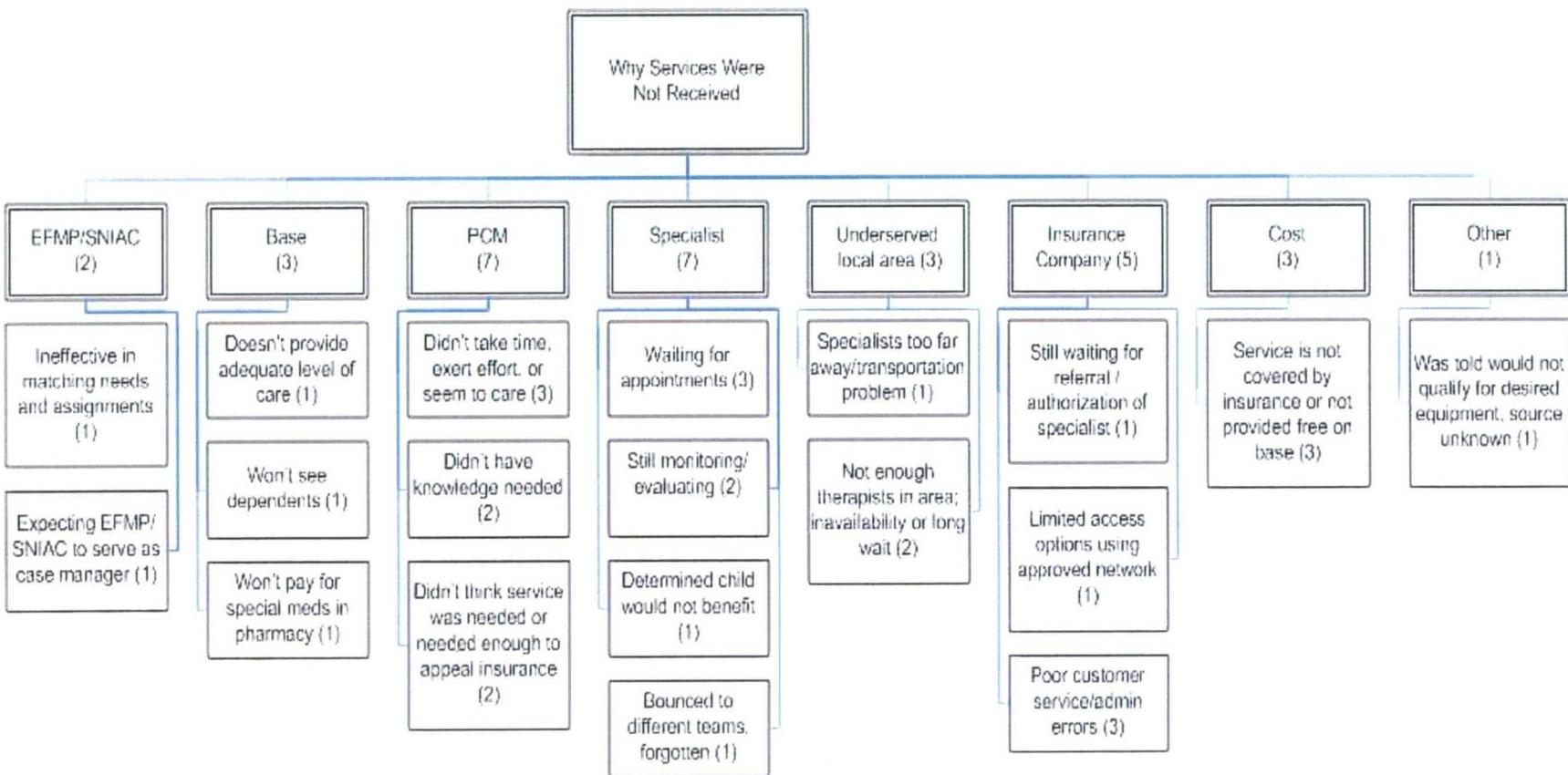
***Geographic location.*** Using the Kruskal-Wallis test for group differences, no significant findings resulted from comparing variances of costs per month, hours spent receiving service per month, or miles traveled, according to Tricare region. However, a significant finding emerged from comparing months spent on waiting lists by geographic locations (Kruskal-Wallis was 12.683, df = 2, p =

.002). Services provided in the north region (Virginia and New Jersey in this study, mean rank = 45.59) were found to have significantly longer waiting times, followed by the west region (California, New Mexico and North Dakota in this study, mean rank = 33.50). The south region (Texas and Mississippi, mean rank = 30.45) reported the shortest times on waiting lists.

**Case manager.** Using the Mann-Whitney U test for group differences between two groups, each of the challenge variables previously examined were explored based on whether the respondent indicated that they had a case manager, or did not but wanted one. There were no significant findings on hours spent monthly receiving services, miles traveled to obtain received services, or months spent on waiting list. However a finding that indicates a possible trend was found regarding the costs per month by the two groups (case manager or none but one desired). For those with case managers, the mean rank was 26.93, for those desiring one it was 21.42, and the Mann-Whitney U coefficient was 210.5,  $p = .064$ , indicating further exploration of this issue would be warranted in future studies.

#### **Why Not Received**

An open-ended item was included in the survey to allow respondents to describe why they believed desired services were not received. Using content analysis, the researcher identified common themes in the responses. A wide range of reasons was described. The researcher mapped the many reasons given for not receiving a service similar to concept mapping techniques (Figure 5).



**Figure 5.**  
**Concept map**  
**of why**  
**services were**  
**not received**  
 $(n = 34)$ .

### ***Summary of Challenges***

In the design of this study, costs associated with obtaining special services, hours spent pursuing and receiving them, miles that needed to be traveled and time spent on waiting lists were all believed to be challenges for families with special needs children. The respondents confirmed that these are each differentially challenging in differing circumstances, at times and in some situations more than others, and that there is a great deal of variation according to the type of care sought, the source of service provided, and the geographic location. The lack of sufficient data to conduct multivariate analyses prevents the researcher from exploration that might further refine these findings, but suffice it to say here that military families who are mobile are likely to experience changing challenges throughout the course of their children's lives. Because of the geographic variability of service delivery systems and the variances inherent in different types and sources of services, these challenges are unfortunately inequitably dispersed. A surprising finding was that the involvement of a case manager did not seem to differentially affect these challenges on military families, indicating that having a case manager may not be as strong a mediating influence as intended. Further study with larger number of people is warranted to explore this in more detail.

### ***Question Four: Perceived Career Impact***

**What do AF families believe is the impact on the military career of having a special needs child?** The database representing persons was used for these analyses, versus the one developed for incidents of service. Three

variables were designed to address this question specifically. One asked respondents to rate the impact of the severity of the child's need on the AF career, one asked the reluctance or concern of the sponsor to identify as a special needs family in the assignment system, and one asked the likelihood of leaving military service due to the special need(s).

#### ***Frequencies on Specific Items***

Across the 43 respondents who rated the severity of the child's needs according to impact on the AF career, 21 indicated it had a mild effect, 15 indicated the need had a moderate effect on the career, and 7 reported a severe impact on the AF career. The mean of this 3 point scale was 1.67, with a standard deviation of 0.747.

The reported concern of the sponsor to enroll in the special needs program, which formally identifies an ongoing special need and complicates the assignments determination process, was also used as a measure of perception of impact on career. Forty-five respondents provided an answer to this item on the survey, 16 were not concerned about enrolling. Nine were reportedly very concerned, and these 25 persons made up the two extreme ends of the 5-point Likert type scale provided for response options. Twenty sponsors therefore reported being somewhere between not concerned at all and very concerned. Another way of describing this is that the mean level of concern was 2.51 on the 5 point scale, with a standard deviation of 1.53.

A key dependent variable for this study was the respondent's rating of the likelihood of the service member's leaving military service due to the challenges

of rearing a special needs child in a mobile lifestyle. Participants were offered a 5-point Likert type scale as response options, with 1 labeled not likely at all, and 5 labeled very likely. Forty-four persons chose to answer this question, and 26 (59%) indicated that leaving military service was not likely at all. Seven persons reported it was very likely they would leave military service. Eleven, therefore, reported they were somewhere in the middle between these two ends of the response options. The mean found on these ordinal data was 2.09, with a standard deviation of 1.55.

As a group, therefore, about half of this sample reported that the need had a mild effect on the career, as compared to a moderate or severe effect. About one-third reported no concern regarding enrolling in special needs programs, and more than one-half reported it was not likely at all that the sponsor would leave military service.

#### ***Group Differences on Career Impact Variables***

Data were explored using nonparametric measures of group differences across groups of military rank. The range of rank responses had been previously grouped according to junior enlisted, junior officer, senior enlisted, and senior officer.

**Rank.** Using Kruskal-Wallis, there were no significant findings on perceived severity of need according to impact on career based on the four groups of sponsor rank. Likewise there were no significant findings based on grouped military rank (4 groups) on reluctance to enroll in programs or on the likelihood of leaving military service. Overall, there were no group differences on

variables designed to assess perceived impact on the career according to sponsor ranks.

**EFMP move.** The Mann-Whitney U test of group differences was used to compare those who had recently experienced relocation due to unmet needs with those who had not on the outcome variables of perceived impact to the AF career. There were no significant findings on severity of need (impact on career), on reluctance to enroll in special needs programs, or on likelihood of leaving based on EFMP move. This sample did not perceive career impact any differently based on whether they had already moved due to special needs.

#### ***Associations with Career Impact***

Rather than looking only at group differences in perceived impact on AF career, the researcher also explored possible associations between selected variables and the outcome variables of severity (impact on career), reluctance to enroll, and likelihood of leaving military service. Spearman's rho was used to correlate ordinal and ratio level variables with these three outcome variables designed to capture perceived impact. The desire was to determine if there were some relationships between other pertinent variables and these methods of assessing career impact.

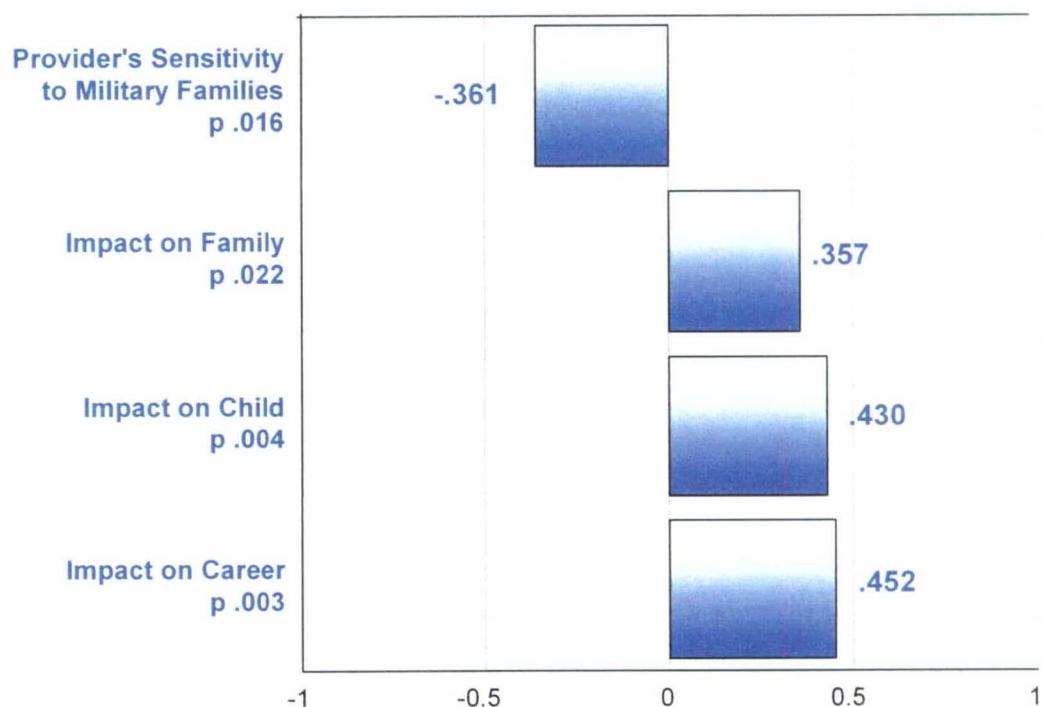
**Severity.** Severity of the child's need based on impact to the child's functioning was correlated with severity based on career impact. There was a significant finding in that Spearman's rho was .429 (p .004). This indicates that increased severity of a need that impacts a child's functioning is also seen by respondents to impact the AF career. Severity of the child's need based on

impact to the family was also found to significantly correlate with severity based on career impact (Spearman's rho = .460, p = .002). These significant correlations are not surprising in that increased severity of a need is understandably going to affect child, family and career to some similar degree. Also, the wording of these survey items involved rating how the severity of the child's need impacted the three separate areas, so it makes sense that they are significantly correlated. However, participants responded differently to the three sections of this item, and there is no 1:1 correlation among the three. It is interesting to note that where the question is *what is associated with higher career impact*, the answer may be higher impact on child and family.

Severity of need (impact on child) and severity of need (impact on family) were correlated with reluctance to enroll in special needs programs. While there were no significant findings between severity (impact on child) and reluctance to enroll, there was a significant correlation between severity (impact on family) and reluctance to enroll (Spearman's rho = .395, p = .01). It may be that each reflects the other in that as the family is stressed by the need, the concern about identifying the family and initiating closer scrutiny on assignments is magnified. As the possibility for separation of the family increases (due to assignment decisions precluding the relocation of the family members with special needs) along with program enrollment, it is conceivable that the impact of the need on the family is greater. This identified relationship based on the correlation between variables needs more study.

Severity of need (impact on child) and severity of need (impact on family) were additionally correlated with the reported likelihood of leaving military service. The first correlation found a significant relationship (Spearman's rho = .43, p = .004) between the severity (impact on child) and likelihood of leaving. Spearman's rho was .357, p = .022, when severity (impact on family) and likelihood of leaving were correlated. Again, this is not too surprising that as the severity of the need is rated higher, the role demands are greater and the likelihood of leaving military service is understandably greater.

From a Spearman rho analysis, Figure 6 shows the strengths of the relationships between the severity of the impact of the child's special need on the child, family, and AF career, and provider's sensitivity to military families, and the likelihood that the AF member will leave the service. These responses indicate no pervasive or strong belief among the study participants that having a special needs child seriously affects the AF members' ability to serve in the Air Force. That said, however, that the relationships shown in Figure 6 are statistically significant with such a small sample sends a substantial, if moderate (Craft, 1990), message that the needs of these families must be met if two of the Force's goals are to (a) retain service members, and (b) see that their children's special needs are met.



**Figure 6. Statistically significant relationships between the severity of the impact of the child's special need on the child, family, and AF career, and provider's sensitivity to military families, and the likelihood that the AF member will leave the service.**

Note the inverse relationship in the first bar in Figure 6. This shows that when respondents felt that the children's providers were less sensitive to the needs of military families, the likelihood that the service member would leave the AF increased. The other three bars in Figure 6 tell us that the greater the impact of the severity of the child's special needs on the child, the family, and the AF members' careers, the more likely they were to leave the military.

***Time enrolled in programs.*** This measure was compared with all three of the outcome variables related to impact on career. There were no significant correlations using Spearman's rho. In a sense, this is a concern because those people who are most experienced with the actual effects of being identified as a special needs sponsor are not any more or any less likely to perceive potential career impacts than those who are new in the program. They still are not convinced there is little career impact even though they have been enrolled the longest. They are not any less likely to leave the military due to special needs than those who are newly identified and enrolled.

***Time on station.*** This measure was examined in relationship with all three of the outcome variables related to impact on career. There were no significant findings, indicating that, for this group of people, there was no relationship between the lengths of time spent becoming familiar with a service location and the measures of perceived career impact. Those "new in town" are no more or less likely to believe having a special needs child might impact their careers.

#### ***Likelihood of Leaving***

One of the goals of the researcher was to identify if it were possible to explain some of the variance in likelihood of leaving military service using the variables developed from the literature review. If a particular topic were identified as partially contributing to those who endorsed high likelihood, future studies and program improvement efforts could be directed toward those topics. The researcher reviewed the list of variables measured for this study, and identified

those most mutable by AF social workers and special needs program administrators. Those that had not already been explored in relation to the likelihood of leaving, above, were examined and results are reported here.

**Case manager.** Using Mann-Whitney U, those who reported that they had case managers were compared to those who did not but said they wanted one, with regard to the likelihood of leaving. This analysis and the next were done at the person (not service) level of analysis. There was a significant finding, the Mann-Whitney U coefficient was 40.00,  $p = .05$ , indicating that those who wanted a case manager but did not have one were more likely to leave (the mean rank for no case manager was 14.64, for those with a case manager it was 9.5. Higher ratings on the likelihood variable indicated more likelihood of leaving the military). This suggests an area on which to focus future program evaluation and improvement efforts—identifying which families want a case manager but don't have one. More research is needed in this area.

**Helpfulness of case manager.** Using Spearman's rho, the rated helpfulness of the case manager, where one was reported, was correlated with likelihood of leaving. A negative correlation was anticipated, since higher helpfulness would logically be associated with lower likelihood of leaving. However, for this sample, no significant finding resulted from this analysis.

**Support of others.** Using Mann-Whitney U as in the previous discussion, those who reported that they have the support of at least one other parent (non-professional) were compared to those who said they did not have that kind of support but wanted to, with regard to the likelihood of leaving reported. There

was no significant finding for this analysis, but the Mann Whitney U coefficient was 65.0 with a significance level of .078, indicating there may be a trend with regard to this analysis. Again, further research is needed.

**Helpfulness of others.** Using Spearman's rho, the rated helpfulness of other non-professionals, where they were available, was correlated with likelihood of leaving. There was no significant finding.

The researcher developed variables from the literature review regarding availability of types of support that have been shown to be important. Additionally, a measure of the subjective meaning (helpfulness) of that support to respondents was included. These were then compared with the reported likelihood of leaving the military to examine if relationships between the variables existed for this sample. From these explorations, it was determined that the area most likely to warrant further investigation is with regard to whether providing desired case management services may reduce the likelihood of leaving the military.

#### ***Summary of Perceived Career Impact***

Findings from this study with regard to perceived career impact indicate that the more severe the need, the more likely the family and sponsor are to perceive a negative impact to the career. It is interesting that, at least for this study, those who had already attained relatively high rank or had already moved due to unmet needs (unable to complete an assignment) did not reflect any differences in the measures of career concern than did those of junior rank or who had not experienced a relocation. Perhaps this finding is due to the overall

finding in this study that participants had no pervasive belief that having a special needs child was likely to impact their career.

One finding that merits further attention regards those not having a case manager but wanting one also indicating a higher likelihood of leaving military service. Of course, with measures of association no causal relationship is claimed, but this is an area most appropriate for further social work research. The role of the case manager is valued highly in both the early intervention literature and in tenets of social work direct practice, and the influence of having a case manager or not on AF special needs families would be an interesting study in its own right.

#### ***Question Five: Satisfaction with Services***

**How satisfied are AF families with the delivery of the services received?** For each type of service described as received by participants an item was provided to rate satisfaction with that service, using a 1 – 5-point Likert type scale. This section provides first the mean, mode, and standard deviation for all satisfaction ratings received, and then explores differences in satisfaction as a dependent variable in groupings by geographic location, type of service received, the source of service received, and whether formal and/or informal supports were available. After this review, measures of association used will be discussed that examined relationships between severity of need and satisfaction, between time on station and satisfaction, and between family monthly income and satisfaction levels.

### ***Satisfaction Reported***

Satisfaction with services received was rated by respondents using a 1– 5 point scale (1 = not satisfied at all, 5 = extremely satisfied). Among the 82 services described that included a satisfaction rating, the following dispersal of results was found. The mean was 3.78, with a standard deviation of 1.40. Interestingly, the modal response was 5, extremely satisfied. When those in the sample received and described services, in general they were quite satisfied with services received.

### ***Differences in Satisfaction by Groups***

Using Kruskal-Wallis tests for group differences, the grouped responses for geographic location, type of service received, and source of service were examined as they affect the variability of satisfaction ratings. For this sample, no significant findings resulted. Using Mann-Whitney U tests for group differences involving two groups, satisfaction ratings were compared with regard to whether the family reported having a case manager or not (but wanted one), and whether they had the support of others available or not (but wanted to). The researcher purposely excluded those who reported that they did not have these supports and did not want to have them from these comparisons. There was a significant finding with regard to case manager. The Mann-Whitney U coefficient for this analysis was 226.00,  $p = .035$ . The mean rank for those with case managers was 30.96, and it was 22.37 for those who desired case managers. Those who reported that they had case managers were far more likely to report service satisfaction than those who did not but wanted one. There was no significant

finding using the Mann-Whitney U test with regard to satisfaction and available support of other persons.

#### ***Variables Associated with Satisfaction***

Using Spearman's rho, several variables were correlated with satisfaction ratings in order to explore relationships between factors believed to impact satisfaction. While numerous variables are known to impact satisfaction, the ones chosen for this discussion were the two severity measures of impact on child and impact on family, time on station as an indicator of community familiarity, and family monthly income level as a rough measure of socio-economic status.

The only analysis among these which produced a significant result was monthly family income. Spearman's rho was .295,  $p = .011$ , indicative of a moderate relationship between income and satisfaction. It is believed that this is not unique to the special services delivery system or to AF families. More study in this area is warranted.

#### ***Summary of Satisfaction***

For those who reported receiving services, this sample was overall quite satisfied with the services received. However, the design of this study does not allow similar description of the satisfaction (or dissatisfaction) of those who pursued services but did not receive them. The only significant finding worthy of mention at this point is the importance of the case manager. For this sample, having a case manager was associated with significantly greater satisfaction in receiving services. While no causal relationship is claimed, this finding, in conjunction with the findings on lower likelihood of leaving military service when a

case manager was involved, lends further strength to the need for more social work research in this area.

#### ***Question Six: Sensitivity to Military Families***

**How sensitive to military family needs do families perceive their service providers?** This variable was measured using an item on the survey which directly asked respondents to rate the perceived sensitivity of their service providers with regard to military family culture. First, the mean rating, mode and standard deviation for this item are reported. Next group differences in perceived sensitivity were examined using Kruskal-Wallis tests, and those results are described. Results from Spearman's rho correlations between selected variables and sensitivity are presented, and this section concludes with a summary of the results found.

#### ***Perceived Sensitivity Reported***

This information was provided by 44 of the 47 respondents to this survey, and was analyzed at the person level, not by the individual services received. The mean sensitivity rating reported using 1 – 5 point Likert type scales (1 = not sensitive at all, 5 = very sensitive) was 3.66, with a standard deviation of 1.45. The modal response was 5, with 18 of the 44 respondents saying that their providers were very sensitive to the unique needs of military families. Six felt that their providers were not sensitive at all, and the remaining 20 reported values between the two ends of the response options.

### ***Group Differences in Sensitivity***

Using Kruskal-Wallis tests of group differences, the variability on perceived sensitivity of providers reported was examined first by groups of service type, then by source. Here the database used was incidents of service, since the type and source are established at the service level, not person level. However, please note that sensitivity was captured once per respondent, with the same value entered for each service that respondent actually received. Therefore, the sensitivity ratings of those who received more services are over-represented in the following analyses than those who received fewer services.

There was no significant finding of group differences on the rated sensitivity with regard to type of service. However, there were significant group differences on sensitivity by source of service (Kruskal-Wallis = 11.63, df = 2, p = .003). Respondents who received services from military treatment facilities were far more likely to report their providers were sensitive to military family needs than either of the two other sources (the mean rank for military facilities was 52.72, for public programs it was 37.43, and for civilian medical facilities it was 31.99). There was no significant finding on group differences by geographic region with regard to perceived sensitivity of providers.

### ***Measures Associated with Sensitivity***

The researcher hypothesized that those who perceived their providers as less sensitive to the military culture might be those experiencing the most stress or vulnerability at the time. Variables indicative of potential vulnerability or higher stress levels that were chosen for examination were the severity of the impact of

the need on child and family (high levels believed stressful), time on station (low values believed more stressful), and income (low levels believed more stressful). Using Spearman's rho, the two variables related to the severity of the need (impact on child and impact on family) were correlated with perceived sensitivity to explore any possible relationship between these variables. This analysis was conducted at the person level, not service level, since each of these items did not vary based on the service received. There were no significant differences.

Using the same method and data base, time on station and family monthly income were also correlated with sensitivity reported. There were no significant results found for this sample. None of the identified variables seemed to have any relationship with the rated sensitivity of service providers. The researcher's hypothesis that increased stress (and its connection to vulnerability) would have a significant relationship with perceived sensitivity was not supported in this sample.

### ***Summary of Sensitivity***

The majority of respondents believed that their service providers were moderately to very sensitive to their unique needs as a military family. However, there was a notable segment of the sample who believed their providers were not sensitive to military families. While there were no significant findings on most of the explorative analyses conducted with regard to this variable, the source of service was found to significantly contribute to the variance reported on sensitivity. This merits further exploration of opportunities for provider education

through public/governmental programs and by Tricare provider relations departments for service delivery enhancement to military special needs families.

***Question Seven: Access and Coping Confidence***

**Do those families who receive services report confidence in their abilities to cope with the demands of rearing a special needs child?** Two items were used to address parent confidence, one which asked about confidence in accessing needed services in the current location, and one inquired about confidence in future coping capabilities, not specific to the current location. Analyses of findings are presented next, separately discussed as access confidence (current) and coping confidence (future). For each type of confidence, the means, modes and standard deviations on the items are reported, as well as reports of group differences found and reports of associations with other variables.

As with the previous variable explored, most of the items relevant to this discussion were measured at the person level, not incident of service level. Thus the level of analysis for the following results provided was respondent, not service received, except where noted.

***Access Confidence Reported***

Forty-three persons provided information which produced the following results from 5-point Likert type scales in which 1= not confident at all, and 5 = very confident. Four were not confident at all in the ability to access needed services in their current location. Eighteen were very confident, and this is reflected in the modal response of 5 for this sample. More people endorsed

feeling confident at a 4 or 5 level ( $n = 25$ ) than the number that reported less confidence at a 1 to 3 level ( $n = 18$ ). The mean access confidence level was 3.72, with a standard deviation of 1.35.

#### ***Group Differences in Access Confidence***

Since groups formed to evaluate the effect of service related variables used the database involving service incidents, those who reported multiple services received are over-represented in this discussion. The individual's rated access confidence was simply repeated for each incident described in the database. This bias aside, the reported levels of access confidence were examined according to type of service and separately by source of service received using Kruskal-Wallis. There was no significant finding based on type of service, and the pre-determined significance level was not met for the analysis of source of service. However, regarding the source of service received, the Kruskal-Wallis coefficient was 5.67,  $df = 2$ , with a significance level of  $p = .059$ , very close to claiming a significant result. There may, however, be a trend with those accessing services at the military treatment facility reporting increasing access confidence, a finding that would not be surprising if replicated in future studies.

In order to examine group differences in access confidence levels according to geographic Tricare regions, the database used was that corresponding to persons, not services, since each was measured at the person level. Therefore there is no over-representation here for multiple service users. There was no significant finding using Kruskal-Wallis for this analysis.

Using Mann-Whitney U tests of group differences between two groups, those who reported having a case manager were compared to those who did not (but wanted one) with regard to access confidence. For this group, a significant finding of Mann-Whitney  $U = 29.5$ ,  $p = .01$ , indicates that those who had case managers (mean rank = 16.55) were significantly more likely to report access confidence than those who desired case managers (mean rank = 9.61).

#### ***Measures Associated with Access Confidence***

Spearman's rho was used to explore possible relationships between severity of need (impact on both child and family) and reported levels of access confidence. These analyses were performed at the person level (not service specific). There were no significant findings with regard to either type of severity rating when correlated with access confidence. Time on station was conceived to be an indicator of familiarity with the local community, and believed to correlate with increased access confidence at the current location. However, there was no significant finding with regard to this comparison using Spearman's rho measure of association.

Similarly, time known of the special need was anticipated to correlate with confidence in access needing services at the local level. For this group of respondents, however, there was no significant correlation found using Spearman's rho. Anticipating that family income, as a rough indicator of socio-economic status, would correlate positively with access confidence, this too was examined using Spearman's rho. This was found to have a significant correlation coefficient of .32, with a significance level of .05. This is seen as a moderate

relationship, giving some indication with this sample that increased income (and possibly socio-economic status) enhances access confidence for special services. However, it is believed that this is not unique to special needs families or to AF families.

### ***Summary of Access Confidence***

Overall, this group of respondents was fairly confident in their ability to access services in their current locations. This may be due to the relatively cohesive military community and to the strong support provided to military families through insurance benefits of both referral systems and levels of third-party payment. It is likely that this group of people would be far more confident than special needs families of similar income levels who were not affiliated with the military, but that is conjecture to be evaluated by a different study.

Those who received services in the military treatment facilities were more likely to report confidence in their ability to access needed care. This is easily understandable since on-base services are centralized and easily located. Additionally, those who reported having case managers were significantly more likely to report access confidence in their current locations. These are areas to address in future service delivery improvement efforts.

### ***Coping Confidence Reported***

This measure addressed respondents' future orientation, or confidence in the ability to cope with the demands of rearing a special needs child into the future. Forty-three persons provided information on this item of the survey. The mean found, using a 5-point Likert type response scale (1 = not confident at all, 5

= very confident) was 3.72, with a standard deviation of 1.32. The modal response was 5, with 18 of the 43 indicating they felt very confident in their future abilities to cope. Two reported feeling not confident at all, and 23 reported values somewhere in the middle between the two response option ends. More than half (25) reported feeling confident about future coping to a 4 or 5-level on this scale, less than half (18) reported the lowest and middle confidence ratings of 1, 2, or 3 on this scale. Figure 6 presents a comparison of means reported on access confidence and coping confidence measures. It is interesting to note the close similarity in these two variables.

Therefore, a good proportion of respondents to this survey reported feeling confidence in coping abilities for the future. However, a proportion indicated they did not feel so strongly confident. The differences in coping confidence are further explored next, according to groups.

#### ***Group Differences in Coping Confidence***

As with other variables in this chapter, the researcher chose to examine variances in coping confidence according to groups of types of services received, sources of services received, and geographic location. Here again, those who reported multiple service incidents are more represented in this analysis than those who did not, as the unit of analysis is service. While there was no significant finding with regard to type of services received, there was a significant result according to source of services received (Kruskal-Wallis coefficient 13.48, df = 2, significant at p = .001). Those who received their services at the military treatment facility were much more likely to report future coping confidence (mean

rank = 54.20) than those who obtained care off-base, either through private sources (mean rank = 34.57) or public ones (mean rank = 32.33).

With regard to differences according to geographic region, the unit of analysis was person. There was no significant finding in this study of future coping confidence varying by geographic region.

The Mann-Whitney U test of group differences was used to examine whether those with case managers reported significant differences in coping confidence. Similar to previous findings, having a case manager (mean rank = 16.35) was significantly associated with enhanced coping confidence (Mann-Whitney U = 31.5, p. = .018) when compared to those who desired case managers (mean rank = 9.75).

#### ***Measures Associated with Coping Confidence***

Both ratings of severity of need (impact on child and impact on family) were compared with levels of coping confidence reported using Spearman's rho to test data from the person level database (versus service incident level). There was no significant relationship found between severity (impact on child's functioning) and coping confidence. There was a significant finding, however, in that severity (impact on family) was found to be negatively correlated with coping confidence, with a correlation coefficient of -.35, p = .025, found. There is an indication that higher levels of severity of needs which impact family functioning more severely are associated with lower levels of confidence in the ability to cope in the future.

Likewise, time on station and time known about the condition were tested with coping confidence using Spearman's rho, as well as family income with coping confidence. These analyses were conducted at the person level and no significant findings were found.

### ***Summary of Coping Confidence***

The responses to the item related to coping confidence were similar in many ways to the responses on the access confidence item. Overall, many of the respondents feel mostly confident in their abilities to cope in the future, but some do not feel confident at all. The source of the service received does differentially impact future coping confidence, with those receiving care through the military treatment facilities more confident for the future. Likewise, having a case manager was associated with higher coping confidence than not having one, but wanting one. Higher severity of need was identified with lower coping confidence. These findings highlight the areas worthy of further emphasis in social work and early intervention services with these families.

### ***Question Eight: Relationship of Other Variables***

**How do the answers to these questions vary by the severity of the need, geographic location, by the involvement of a case manager or other available supports, and by relevant demographic factors (such as family income, time in community, or rank)?** This question has been addressed throughout the previous discussions. While the key questions of the study involved the description of service types and sources utilized by AF families with special needs children, as well as exploring the challenges they face and career

impact concerns, it was important to identify the sub-questions which were explored in examining the topic as a whole. It is of course possible to look at all the combinations of all variables of the study, but the decision was made to focus on those either most critical to understanding this group and their experiences, or most likely to be addressable. For these reasons, no further quantitative results will be described from this study, and the emphasis will change to a more qualitative discussion of the themes uncovered in the open-ended response items. The remaining goal is to "tell the stories" that have not been captured by previous analyses.

#### ***Question Nine: What the Families Say***

**What do these families say about their experiences pursuing specialized services for children with special needs within a mobile military lifestyle?** An important topic addressed by the survey which has not been described to this point is how others are helpful, or not helpful, to them. Whether the persons described were formal service providers or informal sources of social support, the respondents had much to say worthy of consideration. It would be grossly unfair to the participants of this research to merely condense or reduce their thoughtfully provided responses into researcher-driven themes. Since the number of comments provided was not exceedingly large, all of the responses were reported in their entirety verbatim, presented next in headings for ease of display of their thoughts and feelings reported. After these comments are presented, a section summary will close this particular review, followed by an overall summary of study results and conclusions for the entire chapter.

Respondents provided the following comments when asked to elaborate how case managers and other informal support people are helpful to them, or not helpful. Providing them in full allows a review of the wide range of comments and feelings expressed, as well as the complexity of some situations.

***Information/Referral***

"SSgt [name of base SNC], she has helped me a lot with different options and agencies!"

"Helped find specialty docs."

"Provided me with the information needed to find providers"

"The woman at the base is very helpful if we have any medical related concerns."

"Lets us know about the programs available in [state]. This person is the person from the service. It is not another family member on base. I do not know or have not been in contact with other family members on base."

"Answering all questions fully about services our son can receive. Getting our son transitioned to school and getting all therapies he needs."

"He gave us our first pamphlet about the program."

***Direct Service***

"[Name of city] doctors and nurses have been more than helpful with our care for our son."

### ***Problem Resolution***

"We had to schedule our son's surgery date and when we asked for help with some bills, we couldn't get any. We finally had to go through our son's doctor."

### ***Emotional/Social Support***

"Helpful – Therapy."

"They are able to relay their experiences, expectations and POCs. It is good to network with individuals that have or are experiencing a similar situation. Supervisors, CCs, and shirts do not have the first-hand knowledge to assist in the capacity that is needed in this stressful situation."

"Just being able to talk [to] someone going through the same thing."

"Advice on various doctors, share experiences and moral support."

"Organization that provides fun opportunities for kids...helps find social activities."

"They just understand what we go through daily having a special needs child and having to deal with work too."

"They were having the same difficulties as we were. Not finding resources. Or finding resources, then not being able to afford them."

### ***Other***

"The case manager is helpful in arranging only ECI services, which aren't extensive enough to manage our extreme situation. No one is there to help us manage all aspects of our son's care, medically and therapeutically. I thought the EFMP office would do that, but they just accept/decline our future assignments."

"I have an excellent State case manager that the *Air Force* coordinator could learn alot from. AFPC tells you to check in with the Special Needs Coordinator. So I did, this would be the 2nd base now. I've experienced a severe AF COORDINATION breakdown. The Air Force DESPERATELY NEEDS to have a body sitting at AFPC, that truly works closely with the Families (over the phone/e-mail, etc) and with losing/gaining base coordinators. Base coordinators should be contacting local agencies on behalf of Families prior to their arrival, ASSISTING with the setting up of meetings with base agencies and contacting state programs (i.e. from inprocessing to early intervention programs) that Families like mine (single parent) don't have to stress out because of the already long laundry list of things to get done prior/after a PCS. Child care was one of the many worst things for me to get, because I still had to inprocess (base policy tells us to be in uniform w/o children). If the coordinator would have called ahead to base agencies, base agencies should have an exception to policy for single-parents with disabled babies that need to inprocess . . . I would think that was the least base agencies could do for us. I have many more wonderful examples along my journey that need to have a total REVAMP. From my experience, I think the Air Force so far have been one of the WORST services that don't have their act together in this Special Needs Coordinator position. This is not an attack on the Air Force as a whole, I like the Air Force as a career, but in all honesty we are lacking attention to detail and heart in so many areas."

"I have next door neighbors that have a special needs son. The husband is a First Sergeant and the wife stays home. They personally get involved with

me and my daughter and assist as best they can. They have been going through the trials and tribulations 12 years longer than me and so they have the heart to help. However, I didn't know them before I arrived at this base, so it's still a Coordinator/whomever's job to assist 100%/the best they can. I've had to endure things that should not have to be endured if someone was doing the right job. But I really don't believe the job responsibilities are specific enough to properly assist Families needs the right way . . . and that's what needs to be revamped. Also, I can bet that the people that sit in positions of authority working on Special Needs Coordination programs for example, don't have the experience and knowledge needed to perform this job, i.e. not having an immediate disabled family member of their own. Experience tells us we have to live it in order to be any good to anyone. Maybe one of the positions of authority needs to be a Family member like me before the program starts working for me and not against me."

"EFMP program determines that you can or cannot go to a location after orders are given to the military member. In order to find out if medical professionals exist at a location you want to place on your wish list you must call the bases pediatrician and if you are lucky a nurse may bother to talk to you and help you find out which hospitals they refer to and how far away they are. Then as a family you have to decide if the specialists exist and then decide to place that base on your wish list. As a previous relocation officer now separated from the Air Force to take care of two EFMP children I saw numerous military members apply for PCS to bases, get the assignment, then the family gets denied to join the military member due to EFMP status and then the military

member is sent on a two year remote without the family. The military member is told that he/she should not have volunteered for the assignment if the family could not go with him/her. It is a catch 22 you can't find out for sure if your family can go with you until after you have orders and once you have orders you are a volunteer and many times cannot get out of the assignment. At least two of these families were divorced before the two year remote assignment ended. Neither of these military members were vulnerable for a remote assignment at that time and would have never been sent on an assignment without their families if they had simply known not to apply for PCS to those locations that could not provide services to their families. Based on these situations I have contacted bases in advance and ensured I have a list of Tricare approved specialists that can handle my children's needs prior to my spouse placing these bases on our wish list. This completely circumvents the EFMP system and makes it completely irrelevant for our family. My children require a pediatric pulmonologist, pediatric gastroenterologist, pediatric allergist, ENT, speech therapist, occupational therapist, and physical therapist between the two of them. Based on this long list it is easy to see why the EFMP office does not want to bother to do their jobs and do the leg work to help me see if a base can support our family's needs prior to our PCS orders. This way they only have to check one base and they don't care if my spouse gets sent without us if the Air Force decides he is a volunteer and should still go to where he volunteered to go without his family."

"She has helped do some things but we have only had her for about a month."

## **Summary**

Those among the 47 participants of this study who chose to provide additional comments provided a wealth of information about what it is like to rear a special needs child in the Air Force. Some of their ideas and concerns are integrated in the concluding chapter of this study with regard to items for future research and suggestions for special needs program enhancement.

## **Summary of All Results and Conclusions**

The participants of this study provided information regarding the special needs of their children. They also described the types and sources of specialized services that they desired and received (or did not receive) on behalf of their special needs children in their current locations. Some of the variables used in this study were captured at the person or child level ( $n = 47$ ), and some were specific to the actual service desired ( $n = 112$ ). Most respondents described desiring multiple services for each child included in this research, and 77 services were described as received with additional detail about those services provided. Two of the 79 services reported as received were not described according to the other items asked.

## **Needs**

A wide range of needs was reported, making grouping of these needs into meaningful categories unfeasible. This dilemma addresses a core concern of both special needs families and service providers in the Air Force: the diversity of types of needs among relatively small numbers of people make assignment coordination, specialty care access management, and other forms of support

nearly individualized efforts, specific to each case. Of course, states provide extensive support to special needs children and their families, but only to those who already live within those states. The challenge for the AF and for AF families lies in determining where families should go, both with regard to assignments and relocating families, and in terms of finding and funding specialized care needed.

#### ***Types and Sources of Services***

The predominant type of service desired and received by families was allied health, including to a large extent physical, occupational and speech therapies. In this category is the blending of medicine and education discussed in Chapter II most evident. For allied health services received and described by these participants ( $n = 46$ ), 20 were provided by a public source (likely a feature of state responsibilities under IDEA), while 19 were obtained using medical insurance. Only 5 of these allied health services were received at a military treatment facility, and 2 respondents did not know the source of the allied health services they received. This dispersal of sources reflects the permeation of allied services into the local community, requiring referral and access navigation for newly arrived families.

Seventeen of the 77 services described as received were clearly medical in nature and were grouped together because they are typically provided by physicians. Eight were provided at the military treatment facility, 8 in civilian medical facilities using insurance, and 1 by a private non-profit organization. The source for these services is probably determined by the capability of the base

military treatment facility in that location with regard to the level of specialization needed. This, too, reflects local variability for mobile families.

None of the services related to obtaining medical equipment or medications ( $n = 7$ ) were obtained through public sources for this group of respondents. This is probably due to the fact that they can be clearly related to medical need and therefore paid by insurance where there is coverage. Typically, public funding sources specify that insurance must be the first payor.

While there were only 4 mental health/counseling types of services received, none were obtained at a civilian facility using Tricare even though that coverage does exist. Two were received at the military treatment facility, 1 through a public source, and 1 from another source (a religious organization). Further study is needed to explore access patterns for counseling or related services by this population. Table 7 displays the results just discussed.

**Table 7**

**Services Received by Type and Source**

<b>Source of service in groups</b>	<b>Type of service, in groups</b>					<b>Total</b>
	Allied Health	Medical/ Physician Based	Meds/ Equipment	Mental Health/ Counseling/ Parenting		
MTF	5	8	2	2		17
Civilian/insurance	19	8	5			32
Public/government	20			1		* 22
Private/non-profit		1				1
Other/don't know	2			1		3
Total	46	17	7	4		* 77

\*Totals include other types not listed here

### ***Challenges***

The diversity of types of services and sources of services contributed to the variance in challenges encountered by those who provided this information. Where services were received, the range of out of pocket expenses per month reported by these families was from \$0 to \$780, with a mean of approximately \$13 per month. This figure is admirably low, and yet the standard deviation of approximately \$38 per month (excluding the outlier of \$780) tells the story of variability in costs incurred. These numbers also describe what military families are willing and able to pay out-of-pocket for services desired; several respondents reported they did not receive particular services because they were not covered by insurance, not provided by public or military sources, and therefore too costly to obtain on their own.

Eighty percent of the participants of this study reported spending nine hours or fewer per month obtaining desired services. This figure may be interpreted as either a challenge or a benefit. Further study is needed to determine if families desire a more intensive level of treatment, and for which types of services, or if spending time obtaining services is seen as a hardship and a deterrent to utilization of specialized services. Whether the time spent was "enough" for respondents was not captured by this study.

One-third of those who described the services received reported that the service was provided in their homes, or at zero miles traveling distance. Over half of the services received ( $n = 41$ ) were obtained by traveling 10 miles or less each way, each service incident. An additional 23 services were obtained by traveling

between 11 and 50 miles each way. Six services were obtained after traveling 100 miles or more, some of these involved special circumstances and were not recurring services obtained on a monthly basis. Therefore most of the services were obtained within a reasonable travel distance, but some families did travel long distances to get the needs of their children met.

Sixty services were obtained after waiting 2 months or less for access to care, 50 of those were obtained with no time spent on a waiting list. Ten were obtained after waiting 3 to 9 months, and one reported waiting 16 months. This last incident is believed to be time spent waiting for a specific provider to be authorized for payment, versus access to a type of service needed. Thus, most were obtained within a reasonable waiting period, but some were not.

Most of the participating families had two or more adults in the family and two or fewer children in the family. Overall, then, there were no pervasive or extreme challenges experienced by this group of AF families with regard to costs, distances traveled, time spent obtaining services or waiting for services, or with regard to the balance of adult time available to child time demanded. There were, however, some families who experienced out-of-the-norm challenges and further study is needed with a larger sample to capture a better understanding of these challenges.

Some significant findings related to challenges and groupings of people or services. Allied health services required more time spent by families on a monthly basis, but whether this is perceived as a challenge or a benefit to these families was not asked. Physician-provided care required more miles traveled to

obtain the service than any other type of service described, as did care for any type of service received in a military treatment facility. Services provided at civilian medical facilities involved more out-of-pocket costs for families, as well as the longest times spent waiting for services. Since this was the most frequently cited source of services received ( $n = 32$  of 77 described), this may represent a growing concern as the AF continues *outsourcing* specialized medical and allied health services away from military treatment facilities.

#### ***Geographic Location***

While one of the intentions of this study was to examine challenges and patterns of service utilization according to geographic location, the low numbers of responses received make any conclusions unwarranted. While the responses received indicated longer waiting times in the north Tricare region, this region was by far the most represented in the sample. More study is needed with a range of responses from all regions in order to address this issue satisfactorily. There were no clear trends in challenges reported in this study based on geographic region.

#### ***Case Management***

Whether respondents reported the availability of a case manager became an item of interest in exploring other variables. Those who indicated that they did not have a case manager but wanted one were significantly less likely to report satisfaction with services and more likely to report higher likelihood of leaving military service than those who had case managers. There was also a trend toward higher costs per month for those without case managers, but this finding

did not meet the criterion established for a statistically significant finding. For most of the specific types of challenges examined, having a case manager did not distinguish any respondents from those who did not. However, a very low number of respondents indicated that they did indeed have a case manager ( $n = 10$  out of 47). Of these, only five reported their case managers worked for the state or public agency contracted by the state to delivery case management services. (Three indicated the insurance company provided their case managers). This is of concern to the researcher because it indicates that many of these families are not being referred to the federally mandated early intervention state-based services where assignment of a case manager is required. Even though it was previously acknowledged that the threshold for identification of a special need is more inclusive in the Air Force than in the civilian sector, examining the severity ratings of the needs reported indicates that many more of these children are entitled to state-based case management services than are actually receiving them.

Interestingly, 20 of the 47 respondents reported they had individualized family service plans (IFSP), which is developed by the case manager with family and provider input. It is curious that twice as many parents reported having an IFSP than having a case manager, since having a case manager seems a prerequisite to having an IFSP. It is possible that for some the IFSP was developed in a previous location, but any plan of this type would be outdated. It is also of great interest to the researcher that eight parents stated that they did not know if their child had an IFSP, indicating a lack of awareness about this

important service tool and their rights under IDEA to participate in service planning. Regardless of whether the particular children involved in this study met the criteria for state-based services, it seems important that all parents of special needs children know about service plans.

Also of concern to the researcher is that two respondents reported the base SNC was their case manager, even though the instructions specified NOT to include SNCs in their answers. Under the current system, the AF SNC is an assignment coordinator, not a special needs case manager. Frequently the SNC is an administrative records technician with no social work training or experience. While some bases still have social workers functioning as SNCs or as supervisors of SNCs, the provision of true case management is a low priority among their many other duties. Understandably, the AF does not seek to replicate services that are existent in the local community. The breakdown appears to be in getting the families to the civilian case managers, but more research is needed on this issue.

#### ***Career Impact***

Almost half of the 43 respondents who answered this item indicated that the severity of the child's need had a mild impact on the AF career ( $n = 21$ ). About one-third ( $n = 15$ ) indicated that the special need had a moderate impact on the career, and 7 reported a severe impact. Approximately one-third of respondents ( $n = 16$ ) reported no concern at all to self-identify as a special needs sponsor, and more than one-half ( $n = 26$ ) reported that it was not likely at all that the sponsor would leave military service. Thus while there were some who

indicated more concern or likelihood of leaving, overall these respondents did not report strong concerns that having a special needs child either had impacted their careers or was likely to impact their careers in the future.

Further exploration of potential concern was conducted according to groups. There were no significant findings on any of the three variables used to assess career impact concerns based on rank of the sponsor or whether the family had experienced an EFMP move when relocated to the current duty station (a relocation due to unmet special needs). Additionally, there were no significant relationships found between time enrolled in special needs programs and career impact, or time on station and career impact. However, the severity of the need(s) based on the impact to child and to family functioning was significantly associated with measures of career impact. For these families, the more severe the need, the more likely negative career impact was perceived. Additionally, the less sensitive to military family needs the respondents perceived their service provider to be, the more likely they considered leaving military service. As mentioned previously, whether the family reported having a case manager or not having one, but wanting one, distinguished groups according to likelihood of leaving military service. This is certainly an area that needs further study, particularly in light of the trend in the AF away from using military resources for case management, and in light of the apparent under-utilization of civilian case managers by this sample.

### ***Satisfaction***

Even though most services received by the entire sample were generally rated as satisfactory, those who reported having case managers were more likely to report service satisfaction than those who did not have a case manager, but wanted one. In combination with the findings reported in the previous section, this lends more strength to the need to further evaluate the role of case management with service delivery enhancement.

### ***Sensitivity***

Significantly more respondents reported that service providers in the military treatment facilities were more sensitive to their needs as military families than any of the other sources. This is not surprising since military treatment facilities are designed to serve military members and their families, and many of the service providers are themselves members of military families. The importance of highlighting this finding regards an increasing trend of downsizing military facilities and outsourcing services, particularly those for family members, into the local communities. Without a formalized initiative to educate civilian service providers, these families are increasingly likely to encounter episodes of service that are not culturally specific or appropriate, an outcome that is counter to the current service paradigm emphasized in the literature (see Chapter II).

### ***Access and Coping Confidence***

Similar to the previous discussion, there was a trend among those families who received services at the military treatment facility reporting more confidence in their ability to access services. While the criterion for level of significance was

not met in this analysis, the significance of the finding ( $p = .059$ ) was close enough to support further exploration of this issue in future studies. This was supported when exploring future coping confidence reported by this sample: families who received services at the military treatment facility were more confident in their future abilities to cope with special needs ( $p = .001$ ). More evaluation is needed regarding how to enhance the access confidence of military families as services are decentralized away from military treatment facilities.

Significant findings were found in the access and coping confidence of respondents by whether they had case managers. This, therefore, seems a promising direction to explore. Strengthening the role of the case manager could target specialized services to families with more severe needs, an aspect found to significantly impact many of the key outcomes of this study.

To this point, specific results have been discussed based on the analyses conducted and the results found using data from 47 respondents. Chapter V will integrate the findings of this limited study with the state of the literature, the goals of the Air Force regarding special needs families, and opportunities for social work to enhance services in this field.

## **CHAPTER V**

### **DISCUSSION**

Thus far, this study has traced (a) the identification of special needs children and their families as a vulnerable population deserving of societal assistance, (b) the specific interests of the military and specifically the Air Force in providing support for these families, (c) the complex evolution of the early intervention and early childhood special education systems, resulting in a mixed and fragmented system, (d) the theoretical premises that provided the framework for the study, (e) the state of the literature explicating the essential elements of an effective early childhood service paradigm, as well as apparent gaps in the current literature regarding mobile military families who have children with special needs, (f) the research questions posed and pursued by the researcher, including the methods used to address the questions, and (g) the results found using available data. As with much of exploratory research of this type, this entire process has raised more questions for further study than it provided any direct answers.

However, it is in consideration of everything mentioned above that the researcher presents the following observations and considerations. This chapter concludes the report of this study by (a) re-emphasizing the limitations of this work, (b) examining the results found in the contexts of the guiding theoretical

and service delivery paradigms outlined in Chapter II, and (c) suggesting ways to enhance the experiences of AF families currently rearing young special needs children, including further research on specific topics identified.

### **Limitations of This Work**

First and foremost, the limited sample size and the purposive sampling method limit the conclusions that can be drawn from this study alone. As mentioned previously, no claim of generalizability to AF families or to families with children who have special needs is made. This study is viewed as an initial exploratory attempt to involve the target population in service evaluation research, and in that aim it has been successful. Recognizing the impact of rapid mobility and the other strains on this population, as well as the imperfections in the sample recruitment methods, it is to some degree remarkable that 47 persons were able to participate.

Multiple topics are yet to be addressed so that the Air Force can fully understand this population and explore their needs, resources and challenges when pursuing services on a national scale. In the attempt to capture the wide range of information needed to address the research questions, the survey instrument itself became lengthy. It may have been overly complicated for many potential respondents, and certainly was not appropriate for those parents with limited reading abilities or for non-native English speakers. Given the voluntary nature of participation in the study with no material incentives offered to respondents, it is important to consider a selection bias among those who returned the survey. This group of participants does not necessarily represent the

norm of AF members who are parents of special needs children. One possibility is that these parents may be struggling more and may be less satisfied with their service access experiences than others, motivating them to speak out when given the opportunity. Their frustration is evident in many of their comments. Another consideration is the possible effect of the relationship between each SNC and the eligible participants at each base. Since the invitation to participate was distributed through SNCs, previous experiences between special needs families and the SNCs might have influenced participation differently across eligible respondents and across bases.

The design of the survey instrument was solely at the discretion of the student researcher, with input received from guiding faculty. As such, it is believed to have face and content validity—yet there were no rigorous analyses of the instrument itself. There are no claims made of criterion validity or construct validity. There were no reliability assessments or factor analyses conducted on the instrument itself. There is, therefore, no evidence that the survey is an adequate measurement tool of the constructs it sought to capture, other than the data received in this study. This makes cautious interpretation of the results essential. It is hoped that the following discussions are held by the reader as limited but promising directions in the vast body of emerging literature regarding the service needs and experiences of special populations.

### **Results in a Theoretical Context**

The literature discussed in Chapter II identified the current service delivery system for early intervention as a mixed/fragmented one, evolved from a

combination of funding sources involving a complex array of services. The results suggest that this is the experience of AF families with children who have special needs. Using the structural functionalism/neofunctionalism theoretical models presented, it is possible to view the system-level rebalancing of structures and functions occurring over time. As the delivery system evolves it becomes more complex, and military sources of health care are no longer able to provide the specificity of service needed by special needs children. These functions are rightfully reallocated to the civilian community, supported by federal and state policies and funding streams.

We can also see in this study the (unintentional) negative consequences of that adaptive upgrading on individuals and families at select points in time. As military family health care has become increasingly complex and expensive, the federally funded insurance system has upgraded. It allows the transfer of more service responsibilities away from military sources and into civilian, specialized communities of health services. However, as has been the case with the outsourcing of health care and other social services for military beneficiaries and retirees, the experience of change is first the perception of loss. Themes are evident in the comments of these families that they feel underserved, possibly even betrayed, by the lack of services available through military treatment facilities and the lack of true case management services available within the military programs. Understandably, the functions of health care delivery or of assignment coordination are now so specialized that AF programs like SNIAC focus only on the AF-related aspects, delegating specialized care and the social

case management of special needs to the more capable civilian sector. Arranging access to these functions has been taken up both by the insurance company, to some extent, and by the public sector administered at the state level. The new challenge is that of integration, and establishment of the proper flow of information among the newly specialized and evolved subsystems.

The AF families of this study often did not know where to go for information, did not feel like they received proper information in a timely manner, and at times received conflicting information in their search for appropriate and adequate services. Using the structural-functionalism perspective, when a system is experiencing disequilibrium due to the adaptive upgrading of its subsystems, the higher levels of the system must be involved in allocation and integration to re-establish stability. This will be discussed further in the section entitled *Suggestions for the Future*.

Social network and exchange theories help make the next conceptual step in the process of adapting to the changing service system. As stated in Chapter II, people with more connections to others, in a variety of social worlds, have access to more information and opportunity than those who do not. In the past, parents have looked to professionals, particularly physicians, for information and support regarding the care of children with special needs. The current managed health care environment both reflects that tradition and solidifies this process. However, several of the respondents indicated, similar to the Hendrickson, Baldwin, and Allred study (2000), that they perceived their primary care managers (PCMs) to be barriers to efficient access to services. In all fairness to

PCMs, those who are active duty or reservists serving at military bases are probably transients in the local community themselves, and not the ideal source of information or referral to specialized local resources. Those who are civilians, practicing in communities with a wide range of culturally diverse clients, cannot be expected to quickly become culturally proficient with the needs and expectations of military families. All PCMs, in their gatekeeper roles with insurance companies, are typically entrusted with containing access to costly specialized services. As medically trained specialists, but not social workers, they are typically not the ideal sources for referrals to publicly provided social or educational services.

These and other factors indicate that AF families need other primary sources of information and referral to the types and sources of services they desire. Their networks need to be expanded, allowing more unrestricted exchange of not only information, but emotional and social support. Comments provided by participants of this study confirmed that just having others to talk to, who understood the challenges they faced, was beneficial. Ways of enhancing this expansion of social and informational networks will be explored further in the *Suggestions for the Future* section.

Both of these theoretical frameworks (structural functionalism and social network/exchange) provide contexts for the findings of this study regarding case managers. While the number of respondents who reported having a case manager is small, the significance of the findings with regard to their enhanced satisfaction levels and decreased likelihood of leaving military service is

important. In structural functionalism, case managers may be the embodiment of the integration role needed by increasingly differentiated sub-systems. Social network mapping shows how the addition of one person opens up new channels of information and opportunity for individuals. This must be even more beneficial when that person is professionally trained to link people with the networks and resources of many others.

Humanist and developmental theories, as well as the strengths perspective and stress theory, remind us not to be too quick in applying possible solutions, such as case managers, to all people. A full 23 of the 47 respondents to this survey said they did not have a case manager, and did not want one. It is not known if this potential relationship was viewed as *disempowering*, intrusive, or how it was otherwise seen as undesirable. These theories remind professionals that clients are effective decision makers for themselves, and there is value in allowing them to make important service-related decisions using available information. Families are likely to know when they can benefit from certain types of services, and when they do not think they need a service they are not likely to benefit from it. What they seem to need most, and what was echoed in these participants statements, is access to the information that professionals have. Response mechanisms that allow families to know their choices and to select from a range of service options, varying at different times, are probably the most desirable. Numerous citations in Chapter II emphasized the primacy of information provision as the primary role of professional teams. The results of this study indicate that many AF families do not believe they are

getting the information they need, but pointing to the lack of case managers is not the only answer.

Changing from a professionally driven model of service delivery to a family-based one was a tenet of the current service delivery paradigm elaborated in Chapter II. The results are next examined to place this study in the context of the greater body of literature regarding early childhood special needs services.

### **Results in the Context of the Service Delivery Paradigm**

In Chapter II, it was argued that an effective service delivery paradigm is (a) focused on families, (b) sensitive to diversity, (c) able to identify needs early from multiple perspectives, (d) delivered in natural environments, (e) integrated and coordinated among service components, and (f) competent to build the capacity of service users and communities. This section will examine the results of this study in these contexts.

#### ***Focused on Families***

In order to be focused on families, services must include caregivers in service planning for their children. They must recognize enhanced family functioning as the goal of services designed to improve the lives of children; in Singer and Powers' (1993) words, they must "minimize suffering and maximize future adaptability" (p. 7). Family-focused services invite evaluation by the recipients of those services and actively involve them as stakeholders in the development of community resources.

It is not clear by the results of this study whether the service delivery system is meeting this standard. Over half of the respondents (24 of 44

answering this item) said they did not have an IFSP, or worse, did not know whether they had one. The IFSP is mandated at both federal and state levels as the vehicle for ensuring parent involvement in service planning. While not all of the children of this study would qualify for early intervention services provided through the public sector, this surprising result indicates that more work and more research is needed to understand how actively involved parents truly are in service planning.

#### ***Sensitive to Diversity***

One item on the survey instrument directly measured the perceived sensitivity of service providers to the needs of military families. Membership in the AF was viewed as a cultural identity in this study. The respondents indicated a relatively high level of perceived sensitivity, a mean of 3.66 on a 5-point scale, but there was a dispersal of ratings indicating that some respondents perceived little or no sensitivity (the standard deviation was 1.45). Perceived sensitivity was higher for those who received services in the military treatment facility, but this accounts for only 28% of the total number of services described as received. This study is not sufficient to determine whether service delivery providers are culturally competent to serve military families effectively. However, there is some indication from these results that further inquiry into this topic is warranted.

#### ***Natural Environments***

The aspect of identifying needs early using multiple perspectives was not addressed in this study. However, the variable *miles traveled* to obtain services was designed as one method to explore if services were being provided in the

families' natural environments. One-third of the services received involved no traveling, an indicator that the services are being provided in the home or other natural environment (e.g., caregivers' home). For the remaining services, the mean number of miles traveled each way to obtain services, excluding outliers, was 22.4 miles, with a standard deviation of 46.76, indicating a wide range of travel distances. Excluding the outliers may unfairly diminish the impact of these findings, and it must be remembered that these numbers do not capture the services NOT received due to travel distances. While civilian families must also travel extreme distances for health care in unique circumstances, more study is needed to explore the effect of these larger distances on families unfamiliar with the local area. Looking solely at these results, there is an indication that AF families are not consistently receiving services in their natural environments.

#### ***Integrated and Coordinated***

The results of this study further indicate that AF families do not perceive the service delivery system to be integrated or coordinated. This was most evident in their responses to the item *why* services that were desired were *not received* and in other comments they freely provided. One theme identified by the researcher is that some of the participants of this study did not understand that the AF no longer directly provides case management services. Some of the frustrations reported are due in large part to expecting the EFMP office/SNIAC program to provide services that they are not designed to provide. Unfortunately, there is no indication that these parents have been told who is responsible for providing them these case management services. Clearly, much work remains to

be done in creating a seamless system of effective and efficient access among the components of military based, civilian private, and public or non-profit service organizations.

### ***Building Capacity***

Examining the final component of an effective service delivery system outlined in Chapter II, these results do not indicate that the capacity or competence of families is consistently strengthened in using available services. Ongoing changes in the health care environment that channel services away from military bases and into the civilian communities result in many benefits for clients. However, for participants of this study, while 72% of services received were provided off-base, respondents indicated both more access confidence and more coping confidence when they received their services on base. Given the mobility of these families, it certainly makes sense that they do not consistently believe they will be able to find services or cope with demands in the future when the sources of needed services remain unfamiliar.

Both the theoretical framework of this study and the elaborated service paradigm for services to young children with special needs emerged from an extensive literature review. Both approaches to viewing the research undertaken share an emphasis on viewing the community or the system as one potential focus of change when individual needs are not met. Both acknowledge the benefits to society of enhancing community capability to support this vulnerable population. Specific methods to do so, among many other possibilities, are discussed next.

## **Suggestions for the Future**

### *Direct Services*

Fortunately, the goals of social work, of early intervention and childhood special education, and of the Air Force with regard to special needs families are all the same. The common challenge is to reduce the strains on these families in order to maximize their inherent functional potential. For all involved, changing the community to better support the families is a viable focus of change. However, as in all aspects of service delivery, it is not likely that adequate resources will be available to do all that is desired.

Using the theoretical premises, the service delivery paradigm outlined in this study and the voices of the participants, it is possible to identify an alternative that draws more heavily on the existent resources—those of the families themselves. Recent expansion of the internet allows ready access to information regardless of scheduling constraints or location. Consistent with the impetus to de-professionalize information sharing, the military has established extensive internet-based portals that provide military families with information on a range of subjects (Jowers, 2005). These existent websites (e.g., militaryonesource.com, AirForceFAP.org, and others) could be strengthened to link with state-based agencies (such as Part B or Part C coordinators), allowing families to locate and explore resources of any state prior to relocating there.

Sections of these sites could be designed for professionals to identify the eligibility criteria for publicly provided services in each separate state (easily available through the National Early Childhood Technical Assistance Center, or

NECTAC.org) and possibly even which assessment tools or measurement instruments are used to establish eligibility. Professionals working with the family in one state could assist in gathering the needed information that will be most useful to the family in making the transition to another state. Families could identify the names and locations of publicly provided services available for their children before making decisions on where to obtain housing in their new communities.

Tricare maintains a website of approved providers in their health service network. By linking this site to the expanded one(s) proposed for military special needs families, this information may be more readily available in conjunction with the service array from public and military sources. It would also be the ideal place to inform families of case management services that are available under Tricare, to educate families about IFSPs, and to keep them informed of important regional variations that may affect their children.

Using this web-based information sharing mechanism, the focus can be on empowering families to link the three major service providers (military, civilian-insurance provided, and public) for themselves. Having this information well in advance of a move would allow enhanced decision making by families and decrease the frustrating dependence on service professionals who are unable to provide all the information needed. Using the structural functional perspective, the federal government (a combined effort of the Departments of Health and Human Services and of Defense) is the ideal source of the impetus to integrate on-line resources of the three major subsystems of this discussion that fall under

the federal level of the system (military, Tricare, and state-based services under IDEA).

Another important aspect of creating more web-based resources for families is the opportunity for parents to pursue information at some times, and emotional support at others. The SNIAC program or other AF entity could provide and monitor chat rooms for military special needs families to use in sharing support, which would draw on the strength of the military special needs community across the world. An emphasis could be placed on sharing positive stories of success and other positive images of families with special needs children coping in their environments. Those experiencing frustrations or needing support would be able to pursue support from others similar to themselves in a relatively safe way, in their natural environments. This is seen as a method to enhance social networks regardless of time on station or geographic limitations. An indirect benefit to families is the ability to provide assistance to others, reframing and strengthening their coping abilities instead of relegating them to be passive recipients of services. Families living in one location could describe service experiences and providers who were particularly helpful to them (or not helpful to them) for the benefit of those families preparing to move to that location. Sections of the website could be dedicated to siblings of special needs children, a group often neglected in support service design (Weatherford, 1986).

Since not all families have computers or are familiar with their use, primary care facilities and family support centers could establish computer work stations in their offices for families to use, with designated support personnel available to

instruct them in how to access this information. The staff time involved in doing so is likely to be much less than providing case management or information/referral services. A wide range of personnel could assist with teaching how to use the internet-based resources, including social workers, nurses, technicians and volunteers. An added benefit to staff is the opportunity to help families channel their complaints to a more productive venue. Professionals will have a forum to link families to sources of support they themselves cannot provide.

This is one suggestion of how the need for both formal and informal support can be provided, in natural environments, building on the strengths of families, and integrating service sectors that seem currently disparate. Additionally, further benefit may be seen in the types of research that become possible through implementation of these ideas. These are discussed next.

#### ***Further Research Needed***

Much more study is needed on all of the issues identified in this study. One type of further research would be a replication of this study, recruiting more respondents. If possible, random sampling would greatly enhance the strength of the study in designing services for all AF families. However, the challenges involved in properly doing so are enormous given the rapid mobility of the families and the need to protect confidentiality.

When evaluating services for potentially vulnerable populations, especially rapidly growing children, there comes a point where the need to implement some form of improvement outweighs the need for further cautious study. With this

particular population, there may be the opportunity to blend direct service with research opportunities. Using the above mentioned suggestion to expand web-based information and social support networks for AF families, an evaluative study could examine the use of such services. Families would be invited to participate in service design and service evaluation, to rate the usefulness of various linked web-based resources along several dimensions. These dimensions could include enhanced service access, enhance problem resolution capabilities, and enhanced decision-making prior to initiating a reassignment or relocation. With participant permission, informal dialogues conducted on web-based closed chat rooms and listservs could be analyzed using content analysis to identify trends that indicate the need for policy or practice changes. Content analyses of on-line discussions could identify concerns specific to military families. These themes could then be integrated into civilian service provider training materials to enhance provider sensitivity to the needs of these families.

Users of these web-based resources could shape the state of the current knowledge about gender differences or education-based differences with regard to the types of information or support needed (Gowen, Christy, & Sparling 1993). On-line interactive sites between military families and researchers are the ideal venue for designing and conducting research that focuses on how military special needs families succeed (Gallagher & Bristol, 1989), not just in where they struggle. By delivering services and conducting sensitive research into the effectiveness of the services provided, social workers can integrate the both-and option when supporting vulnerable populations.

### **Concluding Comments**

Regardless of whether these recommendations are pursued, further study is needed to identify ways in which the Air Force and particularly social workers serving Air Force families can minimize needless suffering and maximize adaptive capabilities. By providing a framework wherein both family demands and military demands can be met, the military can create an environment in which service members maintain a high commitment to both. But first, the military must adapt its family support structures to the families of today (Bourg & Segal, 1999).

This concludes the report of the study conducted to examine the needs, resources, challenges faced, and other experiences of Air Force families rearing young children with special needs. It is believed to be the first attempt to include this population in structured service delivery evaluation across the wide service array in both public and private sectors. While limited, it is a first step in addressing both social work's and the Air Force's goals of supporting families.

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**Non scholae sed vitae discimus - We do not learn for school, but for life.**

(Seneca)

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## **APPENDIX A**

### **Identification Criteria for Special Needs Program**

It is DoD<sup>1</sup> policy that family members who meet the following criteria will be identified in a service specific special needs program.

Potentially life threatening conditions and/or chronic medical/physical conditions requiring intensive follow-up support (such as high risk newborns; patients with a diagnosis of cancer within last 5 years, sickle cell disease, insulin dependent diabetes) or sub-specialty care.

Chronic (duration of 6 months or longer) mental health condition (such as bipolar, conduct, major affective, thought or personality disorders), inpatient or intensive outpatient mental health service within the last 5 years, intensive mental health services required at the present time, including patients under the care of primary care manager or other health care provider.

A diagnosis of asthma or other respiratory related diagnosis with wheezing which meets one of the following criteria:

Routine use of inhaled anti-inflammatory agents and/or bronchodilators

History of emergency room use or clinic visits for acute asthma exacerbations

History of one or more hospitalizations within past 5 years

History of intensive care unit admissions

A diagnosis of attention deficit disorder/attention deficit hyperactivity disorder (ADD/ADHD) that meet one of the following criteria:

A co-morbid psychological diagnosis

Require multiple medications, psycho-pharmaceuticals (other than stimulants), or does not respond to normal doses of medication

Require management and treatment by mental health provider (eg. Psychiatrist, Psychologist, Social Worker)

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<sup>1</sup> Department of Defense

Require subspecialty consultants other than family practice more than twice a year on a chronic basis.

Require modifications of the educational curriculum or the use of behavioral management staff.

Requires adaptive equipment.

Requires assistive technology devices or services.

Requires wheelchair accessibility/housing modifications.

Has or requires Individualized Education Program (IEP).

Has or requires Individual Family Service Plan (IFSP).

**APPENDIX B**  
**Survey Instrument**



USAF SCN 04-084  
Valid thru 31 Aug 05

August 11, 2004

Dear AF Parent of a Special Needs Child:

You are invited to participate in a research study. The study is supported by the U.S. Air Force Special Needs Information and Assignment Coordination Program Manager, and sponsored by the Kent School of Social Work, University of Louisville. The study is being conducted by Dr. Ruth Huber, the Principal Investigator, and Carol Copeland, a doctoral student in Social Work. This letter describes the study to inform your decision whether to participate.

The study will take place at eight (8) Air Force bases. Approximately 300 people will be invited to participate. You were identified because of your enrollment in the Special Needs Identification and Assignment Coordination Program and because of the age of your child with special needs. Your participation in this study will last for approximately 45 minutes, the time it will probably take you to complete the survey. You are free to decline to answer any question that makes you feel uncomfortable.

#### Purpose

The purpose of this research is to gather current information about the experiences of Air Force families who have special needs children under 6 years old. Participants will report and describe their experiences obtaining needed services and how the demands of caring for a special needs child are believed to impact the Air Force career. Geographic differences based on the location of assignment will be considered. Participation is confidential: information that might identify you will not be released to the researchers, to the sponsors of the study, or in reported results.

## **Procedures**

In this study, you will be asked to complete a survey. You may choose if you prefer to complete the survey on paper, or by computer. If you choose to complete this on-line, log into (website). Either method will require approximately 45 minutes. Additionally, any respondent may call the researcher to confidentially provide responses by telephone, or to provide additional information if desired. You are free to decline to answer any item that makes you uncomfortable to answer. The researcher will make no further contacts to participants once the survey is completed.

## **Potential Risks**

There are no foreseeable risks to participating in this study.

## **Benefits**

Although you will not receive any direct benefit from participating in this study, indirect possible benefits of this study include an opportunity to provide information to policy makers and service providers regarding the needs and experiences of Air Force families who have special needs children. Although the information from the data collected may not benefit you directly, the information learned in this study may be helpful to others.

## **Confidentiality**

Although absolute confidentiality cannot be guaranteed, confidentiality will be protected to the extent possible and to the extent permitted by law. The study sponsor, the Institutional Board (IRB) and Human Subjects Protection Program Office (HSPPD), or other appropriate agencies may inspect your research records, but only the Special Needs Coordinators at each base will know your identity. This is the reason for using the identification code; each family's code is listed on this document. The researcher will receive your answers but not have your identity; the Special Needs Coordinator will have your identity to mail you the survey and to make sure you received it, but will not have your answers. The code is used only to help track which responses have already been received, so that no further follow-up will be attempted. The Special Needs Coordinators will not be able to match which family provided specific information, and they will only be given aggregated (combined) answers from all participants involved in the study. Should the data collected in this research study be published, your identity will not be revealed.

## **Voluntary Participation**

Your participation in this research study is voluntary. You are free to withdraw your consent at any time without penalty or losing benefits to which you are otherwise entitled. You may discontinue participating at any time without any penalty or loss of benefits to which you are otherwise entitled.

## **Research Subject's Rights and Contact Persons**

You acknowledge that all your present questions have been answered in language you can understand and all future questions will be treated in the same manner. If you have any questions about the study, please contact Carol Copeland, (502) 254-1539 or ask your Special Needs Coordinator to forward your question confidentially.

If you have any questions about your rights as a research subject, you may call the HSPPO (502) 852-5188. You will be given the opportunity to discuss any questions about your rights as a research subject, in confidence, with a member of the IRB. The IRB is an independent committee composed of members of the University community, staff of the institutions, as well as lay members of the community not connected with these institutions. The IRB has reviewed this study.

The Air Force Institutional Review Board located at Wright-Patterson Air Force Base, Ohio, has also reviewed this study. If you would like to direct your questions regarding your rights as a service member or Air Force family member, you may contact them at (937) 257-4242. They have assigned tracking number #FWP20040034E to this study.

## **Consent**

By returning this survey in the mail or by completing it on line at (website), you indicate that any of your questions have been answered and that you hereby consent to voluntarily participate in this study. You should keep a copy of the consent and information on these pages for future reference if needed.

Thank you for considering my invitation to participate in this study.

Sincerely,

---

Signature of Principal Investigator

Date Signed

---

Signature of Co-Investigator

Date Signed

**Beginning of Questionnaire – Return this page through page 15**

**\*\* Your family's code number is:** \_\_\_\_\_  
(enter this into the website if you choose to complete this survey online)

1. Today's date: \_\_\_\_\_
2. Your relationship to child: \_\_\_\_\_  
(such as mother, father, step-mother, foster-father,  
etc)
3. What is this child's date of birth? List as day, month, year: \_\_\_\_\_

If this date is earlier than 01 October 1998, do not complete this survey for that child. This study is designed for children younger than 6 as of 01 October 2004.

4. What is the diagnosis or condition that this child experiences, which qualifies you for services in the Special Needs Identification and Assignment Coordination (SNIAC) program? If this child experiences more than one condition, name the one that has the most impact on your family life, that requires the most attention, or that seems the most severe.

Name of Condition:  
\_\_\_\_\_

If you are not sure of the name of the condition or the diagnosis experienced by your child, your Special Needs Coordinator can help you get this information.

5. Approximately how long (in years) have you known that your child has this condition or diagnosis?  
\_\_\_\_\_

What effect do you think this condition has on:.....(mark the correct box)

	<b>A mild effect</b>	<b>A moderate effect</b>	<b>A severe effect</b>
6. Your child's ability to function normally?	1	2	3
7. Your family and its daily activities?	1	2	3
8. The sponsor's military career?	1	2	3

9. When did you make your last permanent change of station (PCS)? Report the month and year you arrived at your current duty station.

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10. Did your family make the last PCS move because this special needs child was not receiving needed services? In other words, was it an Exceptional Family Member Program (EFMP) reassignment? \_\_\_\_\_ Yes \_\_\_\_\_ No

11. If you answered yes, which base did you leave for the last PCS?

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12. We know that some people are concerned that reporting a special need might affect their assignments and their AF career, and they are very uncomfortable enrolling in special needs programs. **How concerned was the sponsor about the AF career when your family first enrolled in EFMP or SNIAC?** Please mark an "X" in the box that best describes how the sponsor felt at that time.

Sponsor was:		Mark one "X" here
Not concerned	1	
	2	
	3	
	4	
Very concerned	5	

13. When did your family enroll in EFMP or SNIAC for the first time? The approximate date is fine.

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14. **Do you currently have a case manager, case worker, or service coordinator who works with you to manage the needs and services for your special needs child?** Please do not include the base Special Needs Coordinator when considering your answer.

\_\_\_\_\_ No, we don't want one (If you marked this, skip to question 18 now)

\_\_\_\_\_ No, but we'd like to have one (If you marked this, skip to question 18 now)

\_\_\_\_\_ Yes, we have one

15. In what type of agency or company does the case manager work? If you don't know exactly, describe the agency as best as you can, or describe how you were introduced to the case manager.

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16. If you are working with a case manager or service coordinator at your current location, how helpful has this person been to your child and to your family in finding and getting services that are needed? **Circle or mark the number that best describes how helpful this person is.**

Case manager is:		Mark one "X" here
Not helpful	1	
	2	
	3	
	4	
Very helpful	5	

17. In what way is this person helpful, or not helpful?

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18. Some AF families find other families who know about special needs, and about services that are available. In your current location, do you have contact with at least one **other parent** that provides information about special needs and/or support to your family?

- No, we don't want to (If you marked this, skip to question 21 now)
- No, but we'd like to (If you marked this, skip to question 21 now)
- Yes, we do

**19. How helpful has this person or these people been to your child and to your family in finding and getting services that are needed? Circle the number that best describes how helpful this person is, or how helpful these people are:**

<b>Other support person is:</b>		<b>Mark one "X" here</b>
Not helpful	1	
	2	
	3	
	4	
Very helpful	5	

**20. In what way is this person or these people helpful, or not helpful?**

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**21. Does your child now have a current Individualized Family Service Plan (IFSP) or Individualized Education Plan (IEP)?**

<b>Answer</b>	<b>Mark one "X" here</b>
Yes	
No	
I don't know	

Thank you for giving us all of this information about your situation. The next section asks questions about the specific types of services you desire, pursue, and receive.

**22. The type of service means what sort of specific, professional activity could be provided, or is provided, for your child and family--such as physical therapy, behavior counseling, adaptive equipment, that sort of thing. We don't need to know the specific name of the service provider.**

Sometimes families want or desire a service, but they don't try to get it for lots of different reasons. Also, some families try to get a service, which means they pursue it, but they don't actually get it for lots of different reasons. We are interested in knowing, for each type of service (like speech therapy), if you first of all DESIRED the service, if you PURSUED that service, and then if you actually RECEIVED the service.

Now, list or write all of the types of services you DESIRED or wanted for your child's condition when you arrived at your current duty station. Write the name of each service (for example, hearing aids, or counseling) on a different line, labeled with a letter of the alphabet to the left. If there are more than 4 for this condition, write only the 4 that you think are (or would be) the most important in helping your child and family.

Then, for each service you wrote, check the boxes if you PURSUED (tried to get that service) and also if you actually RECEIVED or are still receiving that service.

NAME OF SERVICE DESIRED	Enter an X if Pursued	Enter an X if Received
Example: Learning American Sign Language	X	
A.		
B.		
C.		
D.		

23. If you pursued any service but did not receive it, give a general description of why you didn't receive it below. If you received all services you tried to get, skip to question 24 now.

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Thank you for continuing to share your experience so that support to special needs families may be improved.

24. The next section addresses WHERE Air Force families are going to pursue and receive the services they need. As you know, there is a complicated mix of services in our country designed to help young children with special needs. Some are provided by the military treatment facility (MTF), some are provided in the local community using Tricare benefits, some are provided to both civilian and military families using government funds (such as Medicaid, Social Security, or programs funded by the Individuals with Disabilities Education Act, IDEA). Some are paid for by the families themselves.

Some services are provided by private foundations or agencies who do not make a profit, but who raise money through donations of others. This type of service

source often focuses on a specific condition, organizations for the blind or those with cerebral palsy. There might be many sources of services in your area.

For each type of service you RECEIVED, listed on the last page lettered A – D, please fill out a table in the next section. It looks at sources of services, how often you are involved in the service, the miles traveled to get that service, the time you spent on a waiting list, and the out of pocket expenses you incurred. It also asks your overall satisfaction with that service. Only describe the services you and your child have RECEIVED in this section.

If you pursued services but did not receive any, skip now to page 13 and question 25.

If you need help with this section or any other section, please ask another parent, your Special Needs Coordinator, or call (502) 254-1539 for the researcher, as needed. You may ask for as much help as you need, from anyone you believe will be helpful. If you prefer not to get help but aren't sure of an answer, just provide as much information as you can.

**USE THIS TABLE FOR SERVICE "A" ONLY**

Name of type of service A: \_\_\_\_\_ (listed on page 7)

If you did not receive the service desired that was listed as "A", skip to the next page now.

Example: Learning Sign Language

<b>What is the source of the service you received?</b>		
<b>Mark all that apply here:</b>		<b>Description</b>
	1	Military Treatment Facility (MTF) or clinic
	2	Civilian medical facility using Tricare or other insurance benefits
	3	Public or Government sponsored program; local, state or federal funding
	4	Private, Non-profit agency that does not bill insurance or Tricare
	5	Other: Please describe:
	6	I don't know the source of this service
How many hours are spent each month using this service?		Number of hours:
How many miles are traveled one way, each time?		Number of miles:
How much do you pay from your own pocket each month?		\$ spent monthly:
How many months were you on a waiting list for this service? If no waiting, or less than one month, enter "0"		Months on wait list:
<b>What is your overall satisfaction with this service?</b>		
<b>Mark one "X" here:</b>		<b>Description:</b>
	1	Not satisfied at all
	2	
	3	
	4	
	5	Extremely satisfied

Now please answer the same questions for the second type of service you reported on page 7. If you did not report any other service received, please skip to page 13 and question 25, now.

**Name of type of service B:** \_\_\_\_\_ **(listed on page 7)**

If you did not receive the service listed as "B" on page 7, skip to the next page now.

<b>What is the source of the service you received?</b>		
<b>Mark all that apply here:</b>		<b>Description</b>
	1	Military Treatment Facility (MTF) or clinic
	2	Civilian medical facility using Tricare or other insurance benefits
	3	Public or Government sponsored program; local, state or federal funding
	4	Private, Non-profit agency that does not bill insurance or Tricare
	5	Other: Please describe:
	6	I don't know the source of this service
How many hours are spent each month using this service?		Number of hours:
How many miles are traveled one way, each time?		Number of miles:
How much do you pay from your own pocket each month?		\$ spent monthly:
How many months were you on a waiting list for this service? If no waiting, or less than one month, enter "0"		Months on wait list:
<b>What is your overall satisfaction with this service?</b>		
<b>Mark one "X" here:</b>		<b>Description</b>
	1	Not satisfied at all
	2	
	3	
	4	
	5	Extremely satisfied

Now please answer the same questions for the third type of service you reported on page 7. If you did not report any other service for this child and this need, please skip to page 13 and question 25, now.

Name of type of service C: \_\_\_\_\_ (listed on page 7)

If you did not receive the service listed as "C" on page 7, skip to the next page now.

<b>What is the source of the service you received?</b>		
<b>Mark all that apply here:</b>		<b>Description</b>
	1	Military Treatment Facility (MTF) or clinic
	2	Civilian medical facility using Tricare or other insurance benefits
	3	Public or Government sponsored program; local, state or federal funding
	4	Private, Non-profit agency that does not bill insurance or Tricare
	5	Other: Please describe:
	6	I don't know the source of this service
How many <b>hours</b> are spent each month using this service?		Number of hours:
How many <b>miles</b> are traveled one way, each time?		Number of miles:
How much do you <b>pay</b> from your own pocket each month?		\$ spent monthly:
How many months were you on a <b>waiting</b> list for this service? If no waiting, or less than one month, enter "0"		Months on wait list:
<b>What is your overall satisfaction with this service?</b>		
<b>Mark one "X" here:</b>		<b>Description:</b>
	1	Not satisfied at all
	2	
	3	
	4	
	5	Extremely satisfied

Now please answer the same questions for the fourth type of service you reported on page 7. If you did not report any other service for this child and this need, please skip to page 13 and question 25, now.

Name of type of service D: \_\_\_\_\_ (listed on page 7)

If you did not receive the service listed as "D" on page 7, skip to the next page now.

<b>What is the source of the service you received?</b>		
<b>Mark all that apply here:</b>		<b>Description</b>
	1	Military Treatment Facility (MTF) or clinic
	2	Civilian medical facility using Tricare or other insurance benefits
	3	Public or Government sponsored program; local, state or federal funding
	4	Private, Non-profit agency that does not bill insurance or Tricare
	5	Other: Please describe:
	6	I don't know the source of this service
How many <b>hours</b> are spent each month using this service?		Number of hours:
How many <b>miles</b> are traveled one way, each time?		Number of miles:
How much do you <b>pay</b> from your own pocket each month?		\$ spent monthly:
How many months were you on a <b>waiting</b> list for this service? If no waiting, or less than one month, enter "0"		Months on wait list:
<b>What is your overall satisfaction with this service?</b>		
<b>Mark one "X" here:</b>		<b>Description:</b>
	1	Not satisfied at all
	2	
	3	
	4	
	5	Extremely satisfied

25. Some children need services from more than four types of specialists. If your child receives other types of service for this one need you are describing, please list them here:

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26. Some children experience multiple needs. If your child has more than one condition, diagnosis or special need that you were not able to describe in this study, please list them here:

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27. Estimate the TOTAL amount of money you spent during all of last year from your own pocket for every condition this child experiences and every service used, including those you did not describe above.

\$ \_\_\_\_\_

28. Please indicate below how confident you are that you can find and receive the services your family and your child need in your current location because of the help that you have received.

How confident are you in finding services?	Mark an "X" here:		Description
	1	2	
	3		
	4		
	5		Very confident

29. Please indicate below how confident you feel that you and your family can cope with future demands and challenges in caring for your special needs child because of the help that you have received.

<b>How confident do you feel about coping in the future?</b>	<b>Mark an "X" here:</b>		<b>Description</b>
		1	Not confident at all
		2	
		3	
		4	
		5	Very confident

30. Please indicate below how sensitive your service providers have been in your current area about unique military family needs and characteristics.

<b>How sensitive do you find the providers are about military families?</b>	<b>Mark an "X" here:</b>		<b>Description</b>
		1	Not sensitive at all
		2	
		3	
		4	
		5	Very sensitive

31. Having a child with special needs can place a lot of stress on families, and so can managing those needs in a military lifestyle. It is not unusual to think about leaving the military due to the difficulties managing special needs.

Please indicate below how likely you think it is that your family will leave military service due only to the difficulties caring for a special needs child. Circle the number that is closest to the way you and your family feel right now.

<b>How likely is it you will leave military service because of special needs?</b>	<b>Mark an "X" here:</b>		<b>Description</b>
		1	Not likely at all
		2	
		3	
		4	
		5	Very likely

32. Demographics: The following questions will help us see in what ways the participants in this study are similar or different compared to other participants.

Question	Answer
How many adults live in the same home with this child, for most of the year?	
How many children live in the same home most of the year, including this child?	
What is the rank of the child's sponsor? (If both parents are AD, give the highest rank)	
Does this child live in government housing most of the time?	Mark here:
	NO
	YES
Total take-home monthly income* (see below)	\$
Monthly BAH received, if applicable	\$

\* Explanation: What is the family's total MONTHLY take home income (after taxes), including allowances, child support, etc? Please report only on the family with whom the child lives most of the year. Also, include only the income that is money or cash, not the value of food stamps, government housing, or other benefits that are not provided to families in cash. If you received Basic Allowance for Housing income, include it in the monthly income figure, then also report just the BAH amount separately so adjustments may be made for fair comparison among families in both types of housing.

## CONCLUSION

You have completed the survey! Thank you so much for taking the time to do this. Your answers are very important in advocating for the concerns of special needs families throughout the Air Force, across the country.

This survey has not been an easy one to complete. If you would like to talk more about your answers, or give more information that you could not put on this form, you are able to do so in this study. However, in order for the researcher to contact you, you would need to provide some personal information and that would, of course, mean the researcher would have your identity.

In that case, the researcher will maintain the confidentiality of any person or family who wishes to be contacted to discuss this questionnaire further. Your name or other identifying information will not be released to any other party as the results of this study are submitted.

If you wish to provide more information that could not easily be submitted on this survey form, and you understand that your identity would be protected by the researcher, call (502) 254-1539 to schedule a time for the researcher to call you back (to keep your cost as low as possible). You do not need to call unless you choose to give more information.

#### **ADDITIONAL INFORMATION**

If you or someone in your family is experiencing a lot of stress related to the demands of caring for a special needs child, or due to the stress of a military lifestyle, free and confidential counseling is available to you. Call your local military treatment facility (hospital or clinic), or talk to your health care provider for information about how to pursue this type of service in your area.

Your Special Needs Coordinator may also have some information for you about specific supports you may be eligible for because of your special needs family member. If you would like to meet another family who could help you, or if you would like to serve as a mentoring family for a new AF family in your area, please let your Special Needs Coordinator know.

The Family Support Center at each base also has many resources for AF families, and maintains an information and referral service for a wide range of services that are available. Please consider contacting your Family Support Center either to learn more or to volunteer.

**THANK YOU!**

## **CURRICULUM VITA**

Carol Copeland  
Major, USAF, BSC  
Date of Rank: 01 Dec 01

### ***Education***

Currently enrolled in doctoral studies, Kent School of Social Work, University of Louisville. Cumulative grade point average (GPA) at completion of classes, 4.00

- |      |  |
|------|--|
| 1988 | M.S.W., (Master's of Social Work), University of Houston                                   |
| 1983 | B.S., Family and Child Development,<br>Virginia Polytechnic Institute and State University |

### ***Credentials***

Currently licensed in Texas as a Licensed Master Social Worker, Advanced Clinical Practitioner (LMSW-ACP)

Additionally recognized by the Academy of Certified Social Workers (ACSW) and by the American Board of Examiners in Clinical Social Work as a Board Certified Diplomate (BCD)

### ***Work Experience***

- |                |  |
|----------------|--|
| 1996 – present | Clinical Social Worker, United States Air Force<br>Various positions held including Flight Commander, Chief, Mental Health Element, Family Advocacy Officer, Drug Demand Reduction Officer, Exceptional Family Member Program Officer, and Disaster Response Team Chief. Duties included oversight of all clinical and administrative staff and functions for the operation of community mental health centers on AF installations, US and overseas. Supervised up to 15 military and civilian staff at each location. |
|----------------|--|

Responsible for the integrity and responsiveness of all clinical services, administrative budgets, regulatory compliance, policy development, and for consultation to commanders. Provided direct individual/family/community services related to prevention and intervention of domestic violence, child abuse, substance abuse, and stress related disorders. counseled individuals and families adapting to military-specific situations and in critical incident stress management. Inspected day care/youth facilities for compliance with abuse prevention policies. Performed interviews in support of military security clearances and fitness for duty inquiries, and advised commanders in aspects of unit/community health.

1988 – 1995	Clinical Social Worker, Psychotherapist Various positions including self-employment and hospital-based practice for the psychosocial treatment of children and families. Secured licensure/registration as Registered Play Therapist/Supervisor.
1983 – 1988	Various administrative and community education-related positions including executive secretary in space industry, teacher of English as a Second Language, employment counselor for war refugees.

#### **Recognitions and Awards for Service to Communities**

- Meritorious Service Medal, one oak leaf cluster
- Air Force Commendation Medal
- Humanitarian Service Medal
- Lajes Air Force Base (Portugal), Flight Commander of the Quarter, Sep 2001
- Air Force Materiel Command Company Grade Social Worker of the Year, 1998
- Tinker Air Force Base (Oklahoma) Company Grade Officer of the Year, 1998
- Cannon Air Force Base (New Mexico) Company Grade Officer of the Quarter, Sep 1997
- Cannon Air Force Base Woman of the Year, 1996

#### ***Graduate-level Research***

2004	Survey study conducted for the Kentucky Cabinet for Families and Children, proprietary report: "Supervisor Satisfaction with New Employee Training"
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- 2003 - 2004 Independent study and unpublished manuscript "Early Intervention and the Military Family", a synopsis of current literature and program components for providers caring for special needs children in a military environment
- 2002 Research practicum and unpublished manuscript: "Military Families and Characteristics of Adults Raised in Military Families", a guide for civilian mental health care providers
- 1988 University of Houston, TX, Graduate School of Social Work  
Master's Thesis: "The Relationship between Acculturation Level and Choices of Types of Health Care Providers among Vietnamese Elderly of Houston, Texas"